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Migrant narratives, chronicity and HIV in London

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Declaration

I hereby declare that this thesis has been composed entirely by me and is my own work. No part of this thesis has been submitted for publication or any other degree or professional qualification.

Daisy Fung

Abstract

This thesis explores chronicity amongst a small group of migrants living with HIV and other illnesses in London. It elucidates their engagements and experiences with self-care, particularly in light of tenuous citizenship. Drawing on field work in London from 2010-2011 with support groups for persons with HIV, largely made up of refugees and asylum seekers, I look at how social vulnerability and frustrations of claims to citizenship are crucial factors in creating conditions for doubt – reservations that centre less on living normally with chronic illness, than living and pursuing a life. I suggest chronicity encompasses varying and contested temporalities that place pressure on what the body is expected to achieve and endure. The thesis argues the task is not only to identify sources of injury and suffering, but to consider different manifestations of how people carry on living, and the ordinary ethical orientations emerging therein. It makes a number of interdisciplinary contributions to studies of chronic illness, chronicity, HIV, ordinary ethics, and migration. It brings together subjects of migration and HIV in novel ways. In drawing attention to the accidental converging of HIV, pharmaceuticals and migration, it highlights the unpredictable forms in which citizenship claims take shape, and go adrift. The thesis thus highlights how the basis for social entry, as well as exclusion, is deeply troubled. Being sick with HIV initiates one into systems of care offered by hospitals and charities, and further services for some, without resolving the legal and political-economic barriers to employment and self-sufficiency. For scholars and practitioners working within areas of community and public health, this study adds to research on both the continued importance and limitations of support groups for HIV and chronic illness management. This thesis illustrates how multifaceted support groups are, in the activities and conversation that unfold, and how this diversity is also a matter of recognising the diversity of individuals and collectives within them. It contributes to ethnographies of HIV in terms of chronic illness and chronicity by focusing less on the integration and presence of HIV into everyday routine, than its lapsing into a wider ethos of wellness and optimism, common hardships and distractions. In considering not only how individuals suffer but also how they endure, this work contributes to the emerging body of scholarship on ordinary ethics, and the extent to which the pursuit of good is stitched into both everyday and extraordinary events and negotiations.

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Introduction

In spring 2005, a series of sculptures by British artist Marc Quinn was exhibited in southeast London. This exhibition, entitled “Chemical Life Support,” featured large-scale figures of individuals living with chronic illness. The figures were lustrous and noted for their statuesque beauty. They appeared to be made from marble but were in fact cast from polymer wax mixed with the drugs people took in order to control their condition. Among the figures was the artist’s son who had a milk allergy, a transplant survivor, and an HIV positive woman who was a well-known advocate for HIV positive people across the UK.¹ The works were considered compelling for how they complicated assumptions about illness and disability – portraying bodies that were intact, visually flawless, but revealing little about what lied beneath the surface. Medical anthropologists might challenge the similitude of Quinn’s sculptures – uncoloured, undifferentiated in other ways, resting outside of context – as well as asking if it is indeed pharmaceuticals alone that keep chronic illness from advancing and lend the body an appearance of health and normality. At the same time, Quinn’s figures also seem to speak of bodies no longer required to fight or race against time – but instead are suspended within it – in a period of expectation, a state of abeyance.

This thesis explores chronicity amongst a small group of migrants living with HIV and other illnesses in London. It elucidates their engagements and experiences with self-care, particularly in light of tenuous citizenship. Drawing on field work in London from 2010-2011 with support groups for persons with HIV, largely made up of refugees and asylum seekers, I look at how social vulnerability and frustrations of

¹ <http://www.marcquinn.com/work/view/subject/chemical%20life%20support/#/3122>

claims to citizenship are crucial factors in creating conditions for doubt – reservations that centre less on living normally with chronic illness, than living and pursuing a life. I suggest chronicity encompasses varying and contested temporalities that place pressure on what the body is expected to achieve and endure. The thesis argues the task is not only to identify sources of injury and suffering, but to consider different manifestations of how people carry on living, and the ordinary ethical orientations emerging therein. I look at the broader forms of encouragement and resignation that take shape around bodies considered if not curable, than treatable and stable. My interest in how the ethical is constituted in an ordinary sense points not to the adherence to rules and regulations, but how some aspect of living, ought to be (Lambek 2010). What would it mean to consider small acts and moments of affirmation that one is owed something and/or worth something? What are the wider insistences, reflections and revelations that give depth and breadth to hopes about a life worth trying for?

My informants held experiences punctured by extraordinary events of ill health, departures from home countries and arrivals into new ones, frustrated movements within the city in search of support, and the grief of familial losses and separations. As I spent more time with them, all of who were in the middle stages of life, and as I settled into the compromises of fieldwork that sometimes left little choice but to take note of the quotidian, I found I was gaining more insight into the different ways that a life can gradually become *unmarked*. As Lauren Berlant (2010: 10) has written about the unraveling and dispersal of crisis, “[...] crisis is not exceptional to history or consciousness but a process embedded in the ordinary that unfolds in stories about navigating what’s overwhelming.” Indeed, many informants

had passed certain points of crisis, and yet continued to grapple with the texture and pace of their lives in a place that was not quite home.

The chronicity of HIV

Chronicity has typically been parsed into two broad streams in medical anthropology, one being the presence of an illness as a lifelong condition; and another dimension emphasising time and temporality, especially the extension and prolonging of uncertainty and crisis – be it social, economic or political. This latter definition of chronicity often stresses an intersection of factors and situations that create repeated conditions and circumstances consistently interrupting linear, progressive trajectories of time within the life course. I return to this second reading of chronicity later in the introduction and in other chapters.

At a training session I attended in one charity, a local consultant physician had been brought in to give a presentation about HIV. She said to the group of volunteers as she showed slides of near normal life expectancy with early treatment, “[...] well, now more and more HIV is compared to diabetes, as a chronic condition, that probably is the most common comparison we make now”. The reiteration of HIV’s chronicity, as something that was not life threatening but a condition that could be dealt with on an everyday basis, (albeit, for the rest of one’s life), was a consistent theme.

HIV, or Human Immunodeficiency Virus, is a disease where the body’s white blood cells, responsible for fighting infection, are attacked, thus causing the immune system to become severely weakened. The white blood cells are also known as CD4 cells; and a CD4 count measures the number of cells in a blood sample. Should the

virus advance, causing the body to develop other infections or cancers, HIV becomes AIDS, Acquired Immunodeficiency Syndrome. The virus is treated with anti-retroviral therapy (ART), which limits how much the virus replicates itself in the body, thus allowing the immune system to continue to fight infection. Even with treatment, though, persons affected by HIV continue to be at risk for other conditions and diseases, including diabetes, cardiovascular problems, and cancer. A few of my informants spoke of learning about the presence of TB infection as well shortly after finding out their HIV status. Similar to the difficulty of pinpointing when they think they became HIV positive, those I spoke with suggested TB might have been in their bodies for some time before becoming “active”. Another informant repeated how her HIV was just one of three major health problems she had, the other two being cancer and high blood pressure. One support group attendee in her early sixties said she had a mild form of diabetes, but that she was able to control it with her diet. It was thus not unusual to hear of a host of other minor or major health frustrations in tandem with HIV.

The most basic change to daily routine and regime that living with HIV entails is the taking of medication once or twice per day. Although some medications can be taken without food, many of my informants were urged in support groups to take their treatment with a meal. The guidance given to persons with HIV is not dissimilar from most public health advice on maintaining healthy “lifestyles”. This includes, a balanced diet rich in fruits and vegetables, lean meats and protein, regular exercise and physical activity, sufficient sleep, and abstaining from or limiting smoking and alcohol intake.

Professional guidelines aside though, it was not difficult to gauge how some of the recommendations might be as troubling as they were sensible. Jane Anderson, a London based HIV consultant who has worked extensively on HIV amongst migrant populations, has written about the ways in which the efficacy of a clinician's guidance is often at the mercy of social and economic circumstances. She writes, "High quality clinical HIV care is difficult to access or to deliver in the face of hunger, inadequate housing and high levels of deprivation" (Anderson 2008: 13). Indeed, the relevance of HIV and the benefits of HIV care are radically diluted in light of everyday trials to meet basic needs. A good night's sleep was not routine for informants sleeping on the sofas of acquaintances. Food vouchers and allowances from charities were limited to specific shops and could not cover the higher costs of fresh produce and organic foods.

Comments and reflections on what it actually meant to live well with HIV often suggested a constant, low-level hum of discomfort and irritation with the body's changes and needs. HIV medication taken over a long period of time can create significant changes in the body. These side effects, ironically, become some of the principle issues people with HIV must tolerate. Nausea, diarrhoea and headache are not unusual in the short run. As the body requires more energy to metabolise HIV medication, people frequently complained of ravenous hunger when they were on treatment. One informant told me she misplaced her medication during a flat move and thus had not been taking it – but that she felt less tired, and her appetite had returned to normal. Some forms of medication alter cholesterol levels placing patients at risk of high cholesterol. Treatment over time can also affect how fat is distributed through the body, altering its shape and appearance. Depression,

anxiety and mood changes are further potential psychological side effects from some types of medication. It would appear that the containing of one condition meant a half a dozen more might grow in its place.

Equally, it was sometimes difficult to clarify what the root cause of distress was for my informants. I recall a peer leader in one session reminding attendees that they were all simply getting older as well. These aggravations of the body were elaborated on in a social environment where individuals could speak frankly with little fear of stigma and discrimination. Having understood later the circumstances under which these conversations were held, I appreciated the novelty and relief that might come from exchanging remarks about seemingly “neutral” topics such as groceries and back pain. But rarely did such utterances about biology appear detached from other protests: problems with council representatives, misunderstandings with clinicians, unsavoury landlords, and tight-fisted charity workers. The waters of HIV and social marginalisation are murky. This thesis suggests medical anthropologists give as much attention to the experiential dimensions of migrancy as to the socioeconomic barriers and challenges people face, and explore how chronic illness can be subsumed and reshaped within a wider undercurrent of grievances and injuries.

Tenuous citizenship

My informants passed through different legal categories in the course of their time in the UK, with many arriving as tourists, students and workers. For many, employers and family sponsored and arranged their initial visas. Over time, some had overstayed their visas or lost their documents, but traces of those former

categories remained in how they occupied their time – in the way they continued to look for casual labour, engaged in sightseeing and part-time study, for instance. With a few exceptions, charities sourced the solicitors my informants encountered. Informants spoke of mixed experiences. Some felt solicitors did not give them enough time to explain their situations, others were bluntly told their cases would be promptly dismissed and that they would be sent back to their country of origin. A few reflected on being passed from solicitor to solicitor, who made different requests on their behalf but to little avail. These stories of constant referrals, backtracking and resubmitting of applications appeared more the rule than the exception. They mirrored much of what I glimpsed at a migrant drop-in centre where I did voluntary support work. The bureaucratic and legal processes implicated in securing advice and resources were seldom straightforward.

Asylum applicants in the UK are assigned to a UK Border Agency (UKBA)² caseworker that is responsible for taking down evidence and monitoring their case (British Refugee Council 2013). Some applicants are able to receive financial and accommodation support from the National Asylum Support Service (NASS), the central agency managing asylum claimant support. The weekly allowance for single adults over the age of 18 is £36.62 (Gower 2013). Practitioners and academics alike have criticised the government's policies toward asylum seekers, the way NASS accommodation tends to disperse people far away from their existing social networks, and particularly the restrictions placed on asylum seekers' right to work (Sales 2005).

² As of 2013, the UKBA was abolished and is now known as UK Visas and Immigration (UKVI). However, I have maintained its former name in the thesis, as it was referred to and known by informants and myself during fieldwork.

Refugee status is granted if applicants meet the criteria set out by the 1951 UN Convention Relating to the Status of Refugees, "owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group, or political opinion, is outside the country of his nationality, and is unable to or, owing to such fear, is unwilling to avail himself of the protection of that country [...]" (UNHCR 1951). Applicants given refugee status are granted five years leave with no work restrictions, after which an application can be made to stay in the UK indefinitely. There are other possible outcomes for those who do not qualify for refugee status, which allow applicants to remain for limited periods of time, including protection on humanitarian grounds. In these cases, although individuals do not face the same situations as refugees, it is considered they would not be able to return safely to their home countries.

My informants with pending applications sought leave to remain, but no one introduced himself or herself to me as an asylum seeker. Although one could argue they were in principle, and practice, seeking asylum and refuge in one form or another – this might also be said for those without the appropriate documents or applications. It was difficult for them to articulate what kind of migrant they were exactly, other than one who had “immigration problems”. They entered Britain with explicit purposes of travel, meeting with family and business partners – none anticipated coming to the UK to be a lifelong patient.

Despite the varied categories and channels through which foreigners can enter the UK, I found when speaking to peers and colleagues about the people I worked with for this project, the term “migrant” always seemed much less resonant than “refugee” or “asylum seeker”. Granted, it was less specific than the latter, but it

also did not appear to conjure the same kinds of sentiments. Refugees and asylum seekers have become recognisable objects of anthropological inquiry, as formerly distant others who now reside close to home. More importantly, these groups likely remain compelling for anthropologists given that they are frequently subjects of intense political debate – at once intruder and victim. Further, the rise of charitable industry providing support and assistance to such groups, and acting as mediators on their behalf is not insignificant. However, I was not entirely comfortable with the terms refugee and asylum seeker. I have stuck with the term “migrant” on the whole throughout this thesis to speak of people for whom the UK is not their country of origin and who are residing with or without permanent status (Anderson 2010: 301). I want to maintain the openness of the term whilst bearing in mind the strain that comes with living a long time in one place without being able to call it home. I also want to avoid the more negative, stigmatising connotations of “immigrant”.

Sales (2002) notes a significant shift in attitude toward asylum seekers in the UK took place in the late 1990s. She points out the 1999 Immigration and Asylum Act created new restrictions on rights to appeal, granted the Home Secretary new powers, and transferred support for asylum seekers from that of local authorities to NASS, which has largely unloaded its duties onto other sectors as it:

[...] subcontracts its work to local authorities and voluntary agencies, including refugee community groups. This legislation has created a new social category of ‘asylum seeker’, separating them both in policy and in popular discourse from recognized refugees. NASS operates on the presumption that the majority of asylum seekers are ‘bogus’ and ‘undeserving’, while the minority granted Convention status are the ‘deserving’. [Sales 2002: 463]

The issue of “deservingness” is indeed a key theme and point of contention, especially in regards to migrants entering and seeking to stay on compassionate or

human rights grounds (Willen et al. 2011: 340). At the same time, I think Sales's description glosses over some of the ambiguities and contradictions involved in migrant access to and experiences of care. Undocumented migrants and persons with pending asylum applications, or anyone from outside the European Union (EU) for that matter interested in coming to the UK to work, study or travel, are not entitled to welfare services, reserved for those with British and/or EU citizenship. Citizenship is defined in large part by what is excluded to whom (Marshall 1964). "Deservingness" may be further considered in light of how migrants are deserving of some things but not of others. My informants who were receiving welfare benefits and housing support had been granted leave to remain and thus their entitlements were similar to British nationals. I knew two informants who had not yet had their requests for leave to remain resolved, but who were being housed in council accommodation. These individuals had particularly severe health problems and other long-term conditions on top of their HIV. Another informant also had council accommodation although she did not have health problems as extensive as the other two. Ground transportation was one of the most burdensome expenses and the majority could only attend group meetings that could reimburse their travel costs. Some participants had use of unlimited travel passes. Personnel and authorities within hospitals played important mediators in helping some patients acquire assistance they normally would not be eligible for, but this was not the case for everyone. Charity staff I spoke with said they made an effort to limit any additional funds or grants to clients who were not getting any extra assistance at all outside of their HIV medication.³

³ With one exception, all my informants entered the UK in or well before 2005. Immigration was no

NHS care is organised along the lines of primary, secondary and tertiary care, the first referring to General Practitioner (GP) services, the second to hospital treatment, and the third to care provided in specialist centres. Most HIV care takes place in hospital and HIV treatment remains free of charge for all. However, in 2004, certain groups were highlighted as exceptions to this rule, namely persons with refused asylum applications, undocumented migrants who lacked the appropriate papers or those who had stayed past their visa dates (Anderson 2008: 12). But these rules are often subject to the consultant's discretion. My informants did not report having difficulty accessing HIV medication. What was usually more distressing for people was the lack of funds due to being unable to work, or informal work that was sporadic and poorly paid.

That informants were able to access pharmaceuticals but not social and labour rights – or only in a very informal and ad hoc fashion – spoke to one of the most troubling aspects of care and citizenship, where an HIV positive body is much more recognisable and treatable than a destitute or homeless one. On the other hand, my informants also expressed relief and appreciation for the inclusive nature of HIV care they received, something that they would be hard pressed to find in their home countries.

Informants were crucially dependent on the pharmaceuticals, and more broadly, on the health care provision that monitored their overall health and the additional risks posed by HIV. Ironically, the global health push for availability of and access to ARTs in low-income countries has meant that HIV medication is much less exclusive, and a much more ambiguous reason for staying in the UK. A 2008

less political then than it is now, but restrictions on migrants have grown under the coalition government – changes that focus particularly on introducing charging for use of the NHS and reducing availability of legal aid for non-asylum immigration applications.

ruling by the European Court of Human Rights set a precedent for refusing persons with HIV requesting to stay in the UK in order to continue accessing ART treatment. The landmark case of “N.” concerned an HIV positive woman from Uganda who arrived in the UK in 1998 feeling unwell and was shortly diagnosed with HIV. She made a claim to remain based on the fact that although her medication was available in her hometown, it was limited, and its cost prohibitive. In the judgment it was stated clearly that these claims were insufficient evidence for remaining in Britain.⁴

Despite evidence submitted by her consultant and third party groups that her life expectancy and quality of life would be drastically reduced, the judgment held that these arguments ultimately remained speculative so long as the applicant was not, in effect, dying. It is interesting to note as well how the ruling acknowledged global health’s fight against HIV and its constantly changing parameters and

⁴ http://www.escri-net.org/docs/i/case_of_N_v_the_united_kingdom.

50. The Court accepts that the quality of the applicant's life, and her life expectancy, would be affected if she were returned to Uganda. The applicant is not, however, at the present time critically ill. The rapidity of the deterioration which she would suffer and the extent to which she would be able to obtain access to medical treatment, support and care, including help from relatives, must involve a certain degree of speculation, particularly in view of the constantly evolving situation as regards the treatment of HIV and AIDS worldwide. [European Court of Human Rights 2008]

Interestingly, in the preceding paragraphs, the judgment reaffirms the responsibilities of the applicant’s country of origin and her family for her health, and it confirms that the care the UK state has provided up to the time of the case does not in itself constitute a responsibility to care indefinitely:

48. According to information collated by the World Health Organisation (see paragraph 19 above), antiretroviral medication is available in Uganda, although through lack of resources it is received by only half of those in need. The applicant claims that she would be unable to afford the treatment and that it would not be available to her in the rural area from which she comes. It appears that she has family members in Uganda, although she claims that they would not be willing or able to care for her if she were seriously ill.

49. The United Kingdom authorities have provided the applicant with medical and social assistance at public expense during the nine-year period it has taken for her asylum application and claims under Articles 3 and 8 of the Convention to be determined by the domestic courts and this Court. However, this does not in itself entail a duty on the part of the respondent State to continue so to provide for her.

networks to improve treatment provision. Not surprisingly, numerous HIV charities and activist groups decried the Court's decision as a setback for human rights and for persons living with HIV in the UK, who ultimately would now risk deportation or being sent back to their countries. One representative of a major HIV charity remarked, "HIV treatments are not universally available in Uganda. This decision, and others that will follow from it, is cruel and inhumane. HIV treatment is currently being rolled out globally but in many African countries it is still only accessible to a privileged minority, though we expect that to change" (Carter 2008). Whilst criticising the ruling, she too referred to the changeable nature of social movements to provide HIV medication and the potential for access to improve. The efforts to maintain the profile of HIV medication in poorer countries as an international cause for concern, and at the same time, place equal emphasis on dealing with HIV "at home" as a domestic human rights issue, have not been without problematic consequences.

And perhaps it was precisely such issues of what constitutes sufficient and legitimate victimhood and suffering that made informants' immigration situations and cases so fraught. My informants did not make, at least not to me, fierce assertions or claims of entitlement to ARTs in the UK. Rather, their reflections on the whole seemed more an acceptance of how events had unfolded – and the mutual responsibilities that have evolved therein, such as the responsibilities to take one's medication and follow their doctor's guidance, and their doctor's responsibility to maintain the care they had initiated.

Those individuals I became close with did not apply for leave based on the right to family, although this is becoming a more significant route towards legal

settlement for many migrants. Some of my informants had children and siblings who were studying and working in Britain, but they had not started new families of their own and most continued to live alone. They stressed the considerable lengths to which their solicitors had gone to make the case for how radically their lives would alter for the worse if they were sent home. They spoke often of how “no news was good news”, and they were reassured by their solicitors that the longer their applications queued for, the greater the chances of getting leave to remain – often granted if an applicant has been in the country for ten to twelve years (BBC 2011). Time was a cold but faithful friend. Informants were sometimes impatient for it to speed up, but the speed at which their applications moved, or, rather ironically, the neglect they received, kept their worst-case scenarios at bay to an extent. Their efforts though to manage and maintain their legitimacy in everyday encounters often meant some version or variety of biomedical citizenship was enacted, and perhaps a therapeutic citizenship as well – less the kind outlined by Nguyen (2008) than one which had a wider intent of doing what needed to be done to feel better, and simply to carry on (Kleinman 2014).

What and where is the “good life”?

But what might it mean to join medical anthropology approaches to HIV and migration studies into deeper conversation together? The intersections of HIV, migration, and ethnicity in Britain have been taken up ethnographically in different studies conducted within a variety of disciplines. Lois Orton (2009) has looked at the context of HIV positive persons seeking asylum in the UK. She has focused on factors affecting participants’ resilience, namely the migration journey that resulted

in a separation from previous social support; the stigma of being HIV positive; and the confines and limitations of the asylum system itself (Orton et al. 2012:926). Anderson and Doyal (2005) have alluded similarly to the paradoxical nature of “health” in their study of HIV positive African women in London. They note the reliance on HIV medication and treatment also creates another set of dependencies on social services, the state and the voluntary sector, whose responses and obligations are by no means guaranteed or delivered with equal measure. Despite the different points of emphasis, and the contrasting ways in which we organise and communicate our information, these works, including my own, report very similar results and observations. Rather than find this disappointing and lacking in novelty, I think it is encouraging that shared themes, and a semblance of consensus, emerge about what is problematic about being a migrant and having HIV in cosmopolitan urban centre.

There are several obvious aspects of scholarship on migration that could be helpful for the anthropology of HIV. The theme of movement across (or between) national borders has, understandably, stimulated a wide range of research into public health consequences of the spread of HIV and other infectious diseases. Anthropologists and community health scholars have outlined how groups defined by their transience are more vulnerable to the disease, particularly sex workers, migrant workers or seasonal labourers, and homeless populations (O’neil et al. 2004; Camlin et al. 2014). Another aspect is the significance of ethnic and cultural difference and diversity within populations for understanding behaviour and improving health promotion and intervention, again, with an eye to HIV transmission, prevention and management (Chinouya and O’Keefe 2008).

Writing in a different vein more interested in how diaspora and health have implicated one another, Harper and Ramen (2008) point out the increasingly contradictory positions of migrants as both potential sources of infection and disease, and the very bodies who are responsible for filling staff shortages across the UK's health system. Others have begun to extend this field by diversifying their definitions of health and well-being, encompassing broadened notions of recovery and healing aided not only by biomedicine but forms of religious and spiritual activity and complementary therapies (Ridge et al. 2008; Doyal and Anderson 2005). There are further strands, though, we could explore for elucidating how the experience of HIV and other chronic illnesses may be radically reframed and reassessed.

Looking for better ways to live

The theme of migration typically conjures ideas of cross border journeys, movements and relationships between countries. Anthropologists have written at length about transnational linkages and the development of diasporic communities that take shape across cities and continents (cf. Amit 2012). One cross cutting theme I would like to highlight is the “good life”, namely the quests and trials engendered in pursuit of it.

Pandolfo (2007: 345) draws attention to the nature and significance of finitude for apprehensions of migration's achievements and risks – suggesting “finitude” is an intimate awareness of death. She hints at a wider set of connotations amongst her informants in Morocco contemplating journeys to Europe, focusing on their dealings with “[...] becoming a non-person, of daily violence and death, of the breaking of familial ties, of life ‘shrinking’, of ‘despair’, of the struggle for life and

the risk of death [...]” (Pandolfo 2007: 334). Acts and thoughts of migration are often positioned within a complex nexus of ideas and experiences related to positionings of the self.

That people migrate in search of a better life has become something of a commonplace remark in popular discussions of migration. It is tempting to unify different experiences of migration as ultimately having the same aims, in an effort to establish a common humanity upon which sympathies toward migrants could rest. What Pandolfo brings to light, though, is the extent to which migration is not solely an act of moving from one place to another but a complex striving, a striving that problematises one’s immediate context and moral sensibilities.

Jackson (2008) has pointed to the redefinitions of what makes a good or better life after one has migrated. Writing about Sierra Leoneans who have migrated and settled in London, he suggests that the quest for a better life is elusive – closely entwined with the desire for social legitimacy, reconciling with homesickness, and the realities of being a visitor in another country. Jackson describes the often-conflicting experiences of one key informant. This informant possessed a valid student visa but was still apprehensive about the possibility of being deported. He recounted to Jackson an encounter with Home Office representatives who accused him of working more hours than he was permitted. Jackson writes:

Anyone who has moved from a familiar lifeworld and gone to live in a place where he or she is a complete stranger, linguistically inept, economically insecure and socially stigmatised will immediately identify with Sewa’s intense self-consciousness – the suspicion that people were staring at him, that he was under surveillance, that he was somehow in the wrong, without rights or any legitimate identity. [Jackson 2008: 69]

However, such experiences are not merely the inevitable disappointments of migration guided by unrealistic expectations. Others have noted that the gloomier

dimensions of migration and settlement present occasion for exploring a different kind of labour, particularly those registering within “the heart” (Napolitano 2007; Khan 2013). Khan, writing about Afghan migrants in the UK, frequently pathologised as groups suffering exceptional mental health problems, observes that what might be thought of as exceptional trauma could be reconceived in terms of “[...] individual affective landscape of politics, economy, and violence, without privileging culture, rationalized language, or any one element” (Khan 2013: 523). That is, instead of asking (or only asking) what is the cause of migrant illness, we might also consider how their distress speaks and the terms through which it is mediated. Khan notes that disappointment resulting from unrealised aspirations also produce varied cultural effects and experiences – observing how one informant’s sense of “feeling stuck”, “[...] could be a positive space for mitigating and critiquing the strain of his relentless obligations, the weight of the past, the work of ‘integration’” (2013: 522).

Medical anthropologists might be well positioned to dwell on how individuals portray their circumstances, efforts and constraints, the trajectory they have travelled. Further, anthropologists could ask how they contest and provoke existing categories and representation that appear most available to them, such as “traumatised”, “refugee” or “victim”. This interest in informants’ critiques about the terms in which they are represented or conceived is, of course, not limited to any specific area within anthropology. Individual and social suffering have been consistent topics of interest for medical anthropologists seeking to clarify the structural political and economic sources of bodily symptoms and afflictions. However, considering that the majority of scholarship on migration and migrant

communities tends to focus on aspects of social marginalisation, this area of work could be helpful for rethinking the depth and complexity of what is entailed in working within or reaching outside of one's limitations in defining a good or better life, and what is maintained, altered and discarded in those efforts. The studies noted above highlight especially well how considerations of illness and disease in the context of migration could be guided by slightly different frames of reference, such as the interleaving issues of livelihood, forms of estrangement, and the constant renegotiations that the good life, or the dream of it, demands.

Citizenship and the politics of legitimacy

Second, work on migration has emphasised the continued relevance of citizenship, as a crucial axis upon which numerous issues of social mobility, identity and agency, often coalesce. Citizenship indexes specific membership within and contracts with the nation-state. It is also a crucial instrument and system for making distinctions about political, social and economic rights and entitlements between individuals and groups, and in its own way, enables and legitimises social inequality (Marshall 1964: 70-71). Scholars have shown the impact of contradictory dynamics of acceptance and refusal, by representatives of the state, charitable sector and media. Access to political recognition may not necessarily mean ease in accessing social care provisions. Similarly, migrants receiving health care based on medical humanitarian grounds could be hard pressed to find similar concessions in other areas of life.

In their explorations of citizenship, medical anthropologists have pointed to how disease and illness can function as a means of soliciting broader forms of social and financial support, as part of wider projects aimed at lessening social inequalities.

Guell (2010) has investigated how Turkish people living with diabetes in Berlin initiate their own versions of self-help groups, often as a response to limited health and social resources for ethnic minorities in the city. Sangaramoorthy (2008: 258-259), writing about HIV positive Haitians in Miami, has discussed how their demands for HIV community care reached beyond the treatment of the condition, “They wanted classes that gave them information relating to their daily lives, on issues not only concerning their health or their illnesses, but also about immigration, poverty, housing, politics, transportation, depression, isolation, religion, family and re-socialisation after an HIV-positive diagnosis.” The emphasis on citizenship clearly goes beyond access to health care as a primary channel through which health is attained.

Critical accounts of migration have often problematised the very grounds upon which social and cultural others are made legible and recognisable. Fassin and d’Halluin (2007) notes the growing pressure for asylum seekers in France to show proof of their physical and mental suffering in order to strengthen their claims to stay in the country. Giordano (2008) has looked at the imposition of subjectivities on migrant sex workers in Italy, namely their positioning as “victims of trafficking”, and how narratives of victimhood are necessary for reaching political refugee status, and subsequent entry into physical and mental rehabilitation offered by voluntary and state agencies. The rendering of migrants, and their health, as objects of sympathy or compassion, and how this is implicated in applications for citizenship, is a topic of increasing concern for anthropologists interested in the varied social and political responses to illness and disease amongst migrants.

Although not typically cast in terms of “health”, these matters are not insignificant to constitutions of bodily and mental welfare. I have found these points and themes highlighted by reflections on citizenship useful on several levels for thinking about the ethnographic material in this thesis. Despite the fact that some informants had British citizenship or permission to stay in the country indefinitely, they remained on the peripheries of society: without full-time employment, separated from their families and children, and subsisting on a loose network of formal and informal relations. Conceptual and substantive contributions from work in migration and citizenship encourages a deeper look into criteria for national membership, the rights and resources it affords, how these things are denied or withheld, and the distinctions made between citizens and non-citizens. Crucially, they provoke questions into the fragilities, divisions and contradictions that inhere to experiences of belonging and non-belonging, which have little to do with legal categories and definitions.

It is also worth noting that questions of how migration impacts on HIV infection or inversely, how HIV infection impacts migration, grow tenuous when speaking with individuals and groups wherein it was problematic to clarify the processes, events and incidents through which their current hardships emerged. In considering how issues of migration, itself a complex chain of events and histories, could create cracks in notions of HIV as all-encompassing projects and identities, I think we also acknowledge the indeterminacy inherent in defining what constitutes a life-changing experience, and what lingers as such in the life course. Anderson and Doyal speak of this in their review of interviews conducted with HIV positive African women in London:

[...] it is also important to recognise that for many in this group, the diagnosis was only one element in a turbulent and ever-changing life. The problems of survival as a migrant dominated many women's lives with the illness representing just one of the many challenges to be faced. W59 from Zimbabwe talked about the enormity of an earlier trauma explaining how she had contracted the disease as a result of gang rape in prison, 'I was detained for 30 days and everyday I was raped by different men...I feel I was robbed of my life.' Thus, *an HIV diagnosis may have a very different texture when it represents not a huge disruption in a largely predictable narrative but yet another trauma* laid on top of forced migration, sexual violence and the death of partners and children. [Anderson and Doyal 2005: 1734, my emphasis]

Although their article maintains its focus on participants' HIV illness management and coping strategies, Anderson and Doyal's observation makes it clear that being HIV positive was not a status or experience easily singled out as life threatening or life altering, given that individuals had sustained numerous crises. It is interesting how the different sources of trauma that the authors' note, despite being bracketed, laid bare the accumulation of deeply troubling experiences and histories within which HIV is embedded. I also think their remarks, however peripheral to their larger study, present an invitation to consider more carefully the social and political inflections and insights revealed when a lifelong illness is writ small. Further, the authors' suggestion that HIV was less a disruption than another traumatic event inserted into an existing series of traumas, also points to the significance of querying illness and disease as social symptom and not only the causes of distress and suffering.

Rendering time awry: chronicity as a multifaceted concept

interruption

n

1. something that interrupts, such as a comment, question, or action
 2. an interval or intermission
 3. the act of interrupting or the state of being interrupted
- Collins English Dictionary

Medical anthropologists have elucidated the parameters of living with HIV as a unique illness experience (Anderson 2003; Whittaker 1992; Songwathanana and Manderson 2001; Levy and Storeng 2007). Considerable anthropological attention has also been given to the incorporation of chronic illnesses into different cultural communities and lifestyles (Guell 2012), as well as delving into the politics and suffering disproportionate rates of illness reveal (Rock 2003). A wide range of other chronic states have also been tapped into, including mental illness and disorientation, blood and genetic disorders, capturing rich narrative and reflection on the self, difference and stigma. As Whyte and others have observed, medical anthropology's interest in narrative interpretation and explanation, particularly the shaping of identity through illness, was particularly motivated by diseases that evolved into chronic conditions (Whyte 2012: 64).

The narrative trajectory of illness and experiences has been extensively researched, and this has encompassed both the transition from being unwell to being well, and the ways in which states of illness are maintained, either by virtue of being chronic conditions, and/or the entwining of illness with persistently troubled social, economic and political environments. What intrigues me the most about "chronic" is the problematic of being on the cusp – your life on the line, in a very mundane way. This, though, did not always manifest itself as a question of having something in your body that was life threatening. During field work I started to think about a broader conception of "chronic": the everyday, dull, routine, and habitual. In other words, how it made up the very stuff of anthropology. With becoming "manageable" comes a different orientation in how one conceives of what one's body is capable of – of a newfound normal.

The thesis thus explores chronicity in several different registers. In a large way, it finds significant inspiration in much of the optimism of illness management discourse. It can be a triumph to be able to compartmentalise HIV as a health matter involving mostly doctors and routine medication. Much of the “living positively with HIV” counsel places as much emphasis on managing clinical relationships as it does on self-management at home, work or school, with families, friends and partners. For something as serious as HIV to become chronic in its nature and manageable as such with ordinary daily care is a tremendous relief for many individuals, and one of the first points where reassurance can be given frankly and generously.

However, HIV, and its stigmata, remains in an awkward place. It is a condition just as applicable to “normal”, heterosexual people, across socioeconomic class, and yet, somehow more applicable to those (i.e. “not normal”) with behaviour or social vulnerabilities that make them most “at risk”. Despite the comparisons to diabetes, HIV continues to leave a mark of difference not easily disclosed. Colvin (2011) has made critical observations of the recent shift in public health discourse toward redefining HIV as a chronic disease. He argues that conventional definitions of chronicity employed in these discourses fail to elucidate the realities and risks of HIV and other chronic diseases. Furthermore this shift fits with wider social expectations of chronic illness as something that can indeed be managed, and therefore should be invisible as such. He argues that the triumph of declaring HIV a chronic disease obscures persistent issues of poverty and lack of resources that significantly affect health and illness management, “[...] treatment narratives that celebrate HIV’s long-awaited arrival as a chronic condition mask the persistence of

the local and the global structural conditions that produced vulnerability and infection in the past and continued suffering and poor therapeutic adherence in the present” (Colvin 2011: 31). Thinking about chronicity as an accomplishment means we must also ask about those social and economic variables and environments necessary for self-care to be carried out to its fullest.

I find little to disagree with in Colvin’s comments. People in the support groups spoke of other health problems their HIV, in part, had created due to the weakening of their immune systems, along with socioeconomic struggles that weighed on their physical and mental well-being. In contrast to Colvin, though, I find some conceptual purchase and momentum in chronicity, and likely because I attempt an alternate reading of it. Let me be clear, I do not disagree with astute critiques about the multiple ways in which social and political inequality are masked, either with discussions about those considered most at risk for disease or the triumph of medicine’s innovation in ARTs. And chances are the reader will find traces of this critique in many parts of this thesis. I am reluctant to leave it there, though. I think it is possible to challenge and resist public health definitions of chronicity whilst unpacking them for elements that could be useful for thinking through diverse social manifestations of and engagements with chronic illness.

Rather than focus on how and why participants successfully (or unsuccessfully) integrate HIV and pharmaceuticals into their daily regiment, I emphasise more the ethos of achievement attached to the habitual and the everyday. I also explore how this relates to the shaping of “ordinary ethics” and permutations of the ethical that rely more on implicit comprehensions of the good. As Lambek has written, “ordinary” suggests, “[...] an ethics that is relatively tacit, grounded in

agreement rather than rule, in practice rather than knowledge or belief, and happening without calling undue attention to itself” (2010: 2). Day approaches “the ethical” as “[...] a process of inhabiting the world” (2010: 294). A number of scholars have brought up the question of how the banal may be therapeutic. There is a vast continuum along which a “therapeutic” effect could be defined and achieved, suggesting anything from physical well-being to feelings of safety, anticipation of good things to come, or perhaps simply the assurance of an everyday task being executed with minimal drama or personal effort. Berlant (2008) suggests some ideas about the ways in which emotion and sentimentality provide something of an architecture for agency. However, it is not just enabling and allowing for initiative and action towards fulfilling desires and dreams, but one that gains traction in modes of adaptability and responsiveness to everyday troubles and disappointments, motivated by an “unfinished sentimentality”:

[...] – ‘that tomorrow is another day’ in which fantasies of the good life can be lived – collaborates with a sentimental account of the social world as an affective space where people ought to be legitimated because they have feelings and because there is an intelligence in what they feel that knows something about the world that, if it were listened to, could make things better. This very general sense of confidence in the critical intelligence of affect, emotion, and good intention produces an orientation toward agency that is focused on ongoing adaptation, adjustment, improvisation, and developing wiles for surviving, thriving, and transcending the world as it presents itself. [Berlant 2008: 2]

My exploration of chronicity attempts to broaden it to include the variety of pressures, pleasures and trivialities that emerge from having ownership once again of an everyday. And I attempt to grasp this notion of recovery that is in part defined by its delay. Further, this forces further consideration of how recovery is redefined at

different points in time, emphasising more than just a crisis and affliction in need of “control”.

A comment I received before starting field work pointed out that there was in fact considerable knowledge and information about how disease risk and vulnerability are distributed within a population, but much less about the people this implicated. Taking up this peculiarity of “knowing the risk but not knowing the people”, I have attempted to reframe aspects of this subject matter largely through prisms of urban estrangement and the ordinary. That is, how much of these experiences reflected something about everyday living in an urban metropolis, but also, how were extraordinary circumstances entwined with or cumulated in common instantiations? As Cavell writes, “the little deaths of everyday life” are sometimes the very things that speak most profoundly:

[...] torment, perverseness, disappointment, devastation, suffocation [...] a kind of perpetual preparation for violence that has led me to speak of our dealings among ourselves 'the little deaths of everyday life,' the slights, the grudges, the clumsiness, the impatience, the bitterness, the narcissism, the boredom [...] [Das 2007: xxii]

Part of this thesis attempts to evaluate what it might mean to explore investments and performances that do not connote obvious political gesture. Investments and gestures that speak to wider social constraints and suffering at the very moment that they seek to surpass them.

Desjarlais’s (1994) ethnographic research with mental health patients living in homeless shelters in downtown Boston is instructive. He queries how their reflections and narrations fundamentally challenge what counts as “experience”, and the grounds upon which it is made and recognised as such (Desjarlais 1994: 887). Much of Desjarlais’s discussion, I find, is rich in insights about the rhythm of time as

precisely that which resists anthropological sensibilities about what kind of time, and experiences, ought to be meaningful.

Desjarlais foregrounds the seeming deficiencies in people's days and everyday routines, deeply influenced by the regulations of the shelter, as well as their relationships and history with "the street". Individuals typically spend their time trying to get free cigarettes off their friends, walking, listening to radio, dealing in petty trade and exchange, panhandling and rummaging for discarded clothing and food. He notes that many of his informants have undergone tremendous social disruption in their lives. As such, stasis – when and where little happens – comes with its own therapeutic significance:

The aesthetics of this form of life centre on the pragmatics of stasis, expediency, staying calm, and holding oneself together. Given the basic conditions of life on the streets, finding a smooth day where nothing much happens has its value. Since one way to stop thinking about the cold or other distractions is to step out of the flow of time, the acme of this predilection is the pursuit of timelessness. For many, there is a need for days where hanging in there is good enough. To get away from the constant tensions and the fleeting distractions, some suspend the minutes of a day. [Desjarlais 1994: 896]

Some of my own informants were stuck in periods of waiting, but I think waiting also suggests a certain level of intentionality that one is waiting *for* something. Desjarlais's observations suggest that anthropologists working with transient groups might want to consider how and when waiting might come to an end, or get paused, not because a resolution has been reached or something has finished, but because alternate forms of living within a certain stretch of time are made sensible.

Secondly, there is the idea of chronicity that emphasises the extended nature of crisis and suffering. In this sense, the cyclical nature of something, the difficulty

of breaking it or redirecting it, is highlighted. Crisis and suffering extend along a variety of branches. It could be the burden of a biological condition, or the burden of a social and political situation and history. For the purposes of this discussion, I want to note for now how this notion of chronicity opens up questions and themes of endurance. Chronicity in this sense suggests asking how do people cope and with what strategies and resources. It compels questions about the implications of time for constitutions of the self, bringing together matters of personal identity, life cycle, negotiating what is possible and no longer possible within the confines of one's body. Alcano (2009) has looked at how constructions workers with HIV in Milan maintain their desire to continue working at their jobs in order to provide for their families, regardless of biomedical guidance urging them to slow down and pay more attention to their health. What is at stake are definitions of sources of "strength", as construction workers find their HIV medication seems to physically weaken them, whereas "work", and being able to work, strengthens (Alcano 2009: 125). Chronicity demands thinking about how individuals implicitly or explicitly reframe their lives and its limitations without treating their illness as their sole determinant of identity, health and welfare. Indeed, pre-existing understandings and definitions of what it means to be a good person, partner, parent and/or worker, could very well continue to be the predominant frame of reference and source of meaning.

The questions of how one endures, what endures in the face of illness, the contradictions between lay and expert definitions of health and capability, all have quite different points of focus. Hay (2010) writing about persons with autoimmune disorder in the US, asks whether expectations made of her informants, to cope with their condition and maintain a semblance of productivity, increased suffering for

those who were not able to fulfill such cultural ideals. She remarks, “Listening closely to people with serious illness revealed that narratives of ‘doing something’ had a positive valence and narratives that describe not being able to do something had a negative valence” (Hay 2010: 261). Chronicity thus invites the problematising of social and cultural expectations and valuations of agency. Day (2010) reflects on how the sex workers she met chose the profession they did at the outset in part as a challenge to notions of the private as separate from public economy, but who have maintained their work over time with a different orientation. She observes, “[...] the work of time, which leads an initial morality into an oppositional politics and then an ordinary ethics defined by accumulated experience and habitual skill. The work of time is a work of unique individuality” (Day 2010: 307). Exploring dimensions of endurance also suggests asking how ordinary ethics are reconstituted through, and as a consequence of, time.

Temporality is a key thread running through these varied aspects of chronicity. Another dimension of chronicity that I hope to get across in the thesis is a broader notion of interruption that it imposes. Interruption tends to spur not just experiences of waiting, but specific conflicts and reconciliations with the quotidian, and with one’s own finitude. I would like to suggest that that temporality is particularly robust and tactile through provocations of mundaneness. There are different manifestations of the mundane that could be spoken of: that which is routine, boring, ordinary, and expected. This does not mean though, that these facets are all attributed the same sentiment and value. There can be satisfaction in the routine, and in knowing what will happen in the course of a day. Boredom may hold

opportunities for reflecting on the past, and savouring thoughts of the future, of what could be.

Kelly (2008) has written about the purchase of the ordinary and mundane in contexts of political violence. He observes the insistences to an ordinary life amongst Palestinians in the West Bank, noting his informants' desires to have "normal" jobs in banks and small businesses, and being able to support their families. An investigation of the significance and meaning of the ordinary and mundane is an investigation of moral and ethical reflection, of social situations as they are and what people embedded within them would like them to be (Kelly 2008: 353-354). Writing about his informant, Khalil, who aspired to become an accountant, Kelly notes that many of his participants were similar to Khalil in that they knew little about what ordinary life actually was given the history of violence they have grown up in and still live through. And yet, his informants continue to reflect on stories they have heard about people they have known who have moved on to "ordinary lives", "[...] ordinariness represented a hope to live in an 'ordinary state', where life was benevolently mundane. As such, the search for the ordinary is also implicitly a critique of the status quo, a sense that things could and should be otherwise. There was an ethical charge to the desire for the banal" (Kelly 2008: 365).

Berlant, Kelly, Desjarlais and Day are working in very different contexts and political environments but I think they all highlight the significance of the banal as an entry point into forms of temporality and social experience that frustrate and exhaust, without eclipsing the possibilities of living. There is what has become banal for people on a day-to-day level, but there is also hope for a certain version of it as

seen in Kelly's case, and also in Desjarlais's, wherein a day without argument brings a sense of comfort and relief. I suggest interruption is a useful term as well for thinking through some of these negotiations with constrained time and space, where life and normality are held in a suspended state in some ways, but also that suspension and delay is no less a source of cultural production.

Rethinking biocitizenship in the meantime

'In the meantime': the period of time between two things; the period of time between now and when something is supposed to happen
McGraw-Hill Dictionary of American Idioms and Phrasal Verbs

Approaching HIV as a chronic condition means that there is much less emphasis on social and political appeals to HIV/AIDS as an "emergency", "crisis" or "global epidemic". Granted, some might argue the legal situations of my informants makes them acutely positioned within debates about the urgency of HIV as a life-threatening condition upon which claims to the state can be made. To some extent that was indeed the case. But my interests and field work were not focused on detailing legal processes and judgments, or the exceptionality of HIV. Further, the fact that many of the support groups I visited operated as pseudo-community and advice centres on some level, much of which had little to do with HIV management, would suggest that there was a certain kind of therapeutic citizenship taking shape. However, considering these associations were situated in London, within a complex circuit of charitable agencies and activities, many of which were working similarly on behalf of patients suffering other conditions, it was difficult to gauge the distinctiveness of the HIV label. Moreover, there are differences between the positioning of HIV/AIDS in resource poor settings where disease-specific appeals

have developed a particular legitimacy and function in the arena of global health and international medical humanitarianism, and its purchase in a western capital where diseases may not be singled out with the same degree of political urgency – unless specific viral or bacterial incidents and emergencies arise (Lakoff 2010).

Writing about community responses to HIV/AIDS in the late 1990s in Burkina Faso, Nguyen (2008) describes a series of developments where HIV is drawn on as a means of legitimating demands for further resources. He suggests the social networks and dynamics resulting from this work has created a form of “therapeutic citizenship”:

[...] that is, claims made on a global social order on the basis of a therapeutic predicament. [...] therapeutic citizenship broadens “biological” notions of citizenship, whereby a biological construct – such as being HIV positive – is used to ascribe an essentialized identity, as in earlier forms of eugenics and racial ordering. Therapeutic citizenship is a biopolitical citizenship, a system of claims and ethical projects that arise out of the conjugation of techniques used to govern populations and manage individual bodies. [Nguyen 2008:126]

With some of my informants, HIV was an aspect of their residency applications, but often more as a feature of a wider health profile considered vulnerable for a variety of physical and mental health reasons. Nguyen describes therapeutic citizenship’s operation within moral economies, as “[...] networks of obligation and reciprocity to negotiate access to therapeutic resources [...]” (Nguyen 2008: 126). I am reluctant to employ too heavily this phrasing here, partly because I am not necessarily attempting to outline such a network, but rather to elucidate some of the points of dwelling and articulation that emerge from unfortunate and troubling social positioning, from the gaps between guidance for living and the actual living.

Rose and Novas (2005: 239) have pointed out how experiences and definitions of citizenship closely entwined with biology and bodily capability, defining the concept of “biological citizenship”, “[...] to encompass all those citizenship projects that have linked their conceptions of citizens to beliefs about the biological existence of human beings, as individuals, as families and lineages, as communities, as population and races, and as a species.” This includes notions of what constitutes a functioning, healthy and normal body, issues of responsibilities to health, and more generally, what makes a good body in and for the polity. These features of biological citizenship have been backgrounded of late, as many anthropologists have been keen to identify the role of biology in claims making on the state.

Biological citizenship here has been discussed in terms of the significance and functions of injured or damaged biology as a way of acquiring compensation from national governments, and often gaining the attention of international and human rights institutions. Anthropologists have highlighted the unsettling phenomenon of how demands made in the name of biology and violated bodies are granted rights and political visibility that healthy bodies generally are not (Petryna 2004; Ticktin 2006). These themes have been especially pronounced in work on post-natural disaster aid, industrial negligence and applications for asylum (Kelly 2011; Fortun 2001). Such works have reaped insights into the role of biology, be it in the form of bodily scarring or impairment, in creating grounds for hope: hope in legal situations, with court and welfare systems, nongovernmental organisations and charities. Trauma and mental states are also being looked at in more detail as anthropologists attempt to account for the growing intervention of different kinds of

medical expertise in proving evidence of injury, as well as the evolving of trauma itself into a persuasive category of common humanity that unifies cultural groups (Fassin and Rechtman 2009).

The tactical uses of biology and illness have raised important questions about the relationship between suffering and attempts for justice and recompense. The suffering slot held by, “The subject living in pain, in poverty, or under conditions of violence or oppression [...]” (Robbins 2013: 448), has indeed played an important role in contemporary ethnography as anthropologists have attempted to elucidate circumstances and experiences that challenge and upset ethical and humanitarian sensibilities of the public.

My participants did not report having problems accessing the health system or medical provision, though several speak of their struggles, past or present, with having their applications approved by the Home Office. Grievance though was hardly toward the state alone. Often individual narratives were thick with reference to details related to the different journeys that had marked their time in the city: sleeping on sofas and under desks, dealing with cunning employers and acquaintances, solicitors and administrators who did not live up to their word, children who are too busy or too far to visit, mobile phone companies who sneakily keep one on hold till one’s credit has run out, friends who do not return phone calls.

There were undeniable instances of social suffering and distress, along with everyday irritations and annoyances in the greater order of events and occurrences. Within peoples’ respective legal and medical cases, their physical and mental conditions were probably, with little doubt, quite critical to the kinds of cases they made in justifying their stay in the UK. There were utterances of gratefulness for

being in Britain and the medication – no one I met though, said that they were grateful for having HIV or being sick. The care received did not encourage people to become more ill or to stay unwell for the fringe benefits and sympathy. In other words, HIV illness was not only a means to keep on living, if anything it was supposed to renew expectations of living. As such, I found more resonant the question of how and when hope is actually in others, other institutions, living by your wits, chance, and the good will of strangers.

Thinking about HIV in the context of migration could provide a useful starting point for rethinking and critiquing concepts of biological and therapeutic citizenship, and reassessing the weight and relevance often attributed to them for explaining collective responses to health and illness. In attempting to contextualise migrants with HIV as persons capable of looking after their HIV as a chronic condition to an extent, even in the most troubling of circumstances, I hope to show that biological citizenship may not always sufficiently explain or illustrate how and why people participate in self-care and patient group activities. Further, as discussed above, studies of migration have illustrated the multifaceted dimensions of what compels people to move in the first place, and what compels (or obliges) them to persist and stay. HIV as a chronic illness, in light of long-range, settlement struggles, of the meantime, also suggests that we ask how sustainable and relevant is the “bio” in biocitizenship, which largely speak to situations and moments of emergency.

With HIV becoming more akin to a chronic condition, it demands a rethinking of how it is embedded within a broader set of ideas and sentiments about the good management of self and body. Furthermore, how its particularities and

inflections might be nodes branching out into wider discussions about optimism and positive thinking as social projects, for instance. As some have noted, the immune system, the sources of its strength and vulnerabilities, its contingencies and potential, has become a larger subject of popular and social fascination (Martin 1994).⁵ Medical anthropologists have given steadfast attention to methods and techniques of coping, the incorporation of illness into daily life, along with the pursuit of “the normal” in the finding of love and making of family. They have shown the reframing of HIV as something that does not foreclose normality, but becomes a feature of it, and how the normal inspires meaning and value as much as it speaks of politics and control (Fassin 2009). This thesis also overlaps with ethnographies of support group socialities and engagements (Gatter 1995; Lyttleton 2004), building on their insights about how such therapeutic interventions produce a sense of hope and not only the making of self-regulatory subjects.

Equally, it was not difficult to glimpse aspects of biological citizenship being sick with HIV in the UK afforded people: the medication, hospital care, and the peer/patient meetings. The support groups could be looked upon as sites of biocitizenship, resembling Rose and Novas’s initial definition. Rabinow (2008) has written about biosociality wherein people develop shared identity through common biological conditions. However, I found collective identity on the basis of HIV to be quite weak. Individuals had different legal histories and situations, varied forms of

⁵ The sociality and society that can come with being sick has interestingly taken shape alongside the individualising of health, as a predominantly individual project and responsibility (Mol 2008). Self-management presents seemingly economical and affectively rewarding discourse and tools, attending swiftly to feelings of despair and abandonment, without necessarily being compelled to address their structural underpinnings. There were many dimensions of community HIV care that appeared just as applicable to a person or situation having little or nothing to do with the virus. The enthusiasm and purported benefits of positive thinking and attitude seemed general enough that most people, sick or not, would likely have come across at some point in self-help literature and aphorisms.

accommodation and homelessness, one participant even said to me that each person probably had a different kind of HIV as well, which was affecting them in different ways.

Some have critiqued the biosociality literature for focusing predominantly on patient groups in western societies with good access to resources and often already well acquainted with networking and advocacy.⁶ Guell (2011: 377-378) argues that biosociality takes shape amongst socially marginalised communities as well, in her case, Turkish migrants with diabetes in Berlin. Guell observes that the lack of social resources available is a motivating factor for the relationships and networks developed amongst diabetes patients in the Turkish community. At the same time, there was nothing inherently cohesive or unified about this sociality, as patients frequently had to come to terms with their own diversity of social and professional roles and allegiances:

In the sociality that forms around “Turkish diabetes,” there are those involved in the provision and organization, patients and health professionals, but also those involved in politics, policies, and business. Therefore, local political, and always also economic, arenas inherently influence how diabetes care is delivered and achieved. However, rather than finding separable positions, people occupied multiple, overlapping, and fluent roles. There were not patients, health professionals, scientists, and drug representatives on opposing or distant sides. [Guell 2011: 393]

Whyte puts clearly and succinctly some of the problematic aspects highlighting identities based on health and medical categories:

⁶ During field work I also found myself returning to the question of how collectivity via disease may have as much purchase for researchers and medical anthropologists, in identifying and delineating objects of research and care, as for the people under scrutiny. The fictive kinship provided by a particular health condition offers its own conveniences to research initiative and protocol: in the soliciting of resources, the building of professional identities and associations – in addition to offering informants ways through and out of patient-hood that challenge notions of patients as apathetic, acquiescent, bodies.

[...] focusing narrowly on relations among people with the same health condition excludes all the other relations and domains of sociality that actually fill most of their daily lives. In fact, those other relations may strongly influence the ways that health comes to shape their identities and subjectivities. By defining research problems based on identifications like diabetic, Down syndrome, HIV+, we essentialize, fragment, and decontextualize what is really only part of a life. And it is, after all, *a life and not an identity that people are usually seeking*, as Michael Jackson reminds us (2002:119). [Whyte 2009: 14, my emphasis]

In working with persons not completely well or unwell, who considered themselves both sick and not sick, and often had parallel struggles of establishing home and citizenship, the body was typically held within a liminal state of being neither here nor there. I was compelled to reflect on experiences of the in-progress and unfinished, neither positioning people as “asylum seekers” and “refugees” in crisis (Malkki 2002: 356), or as “biocitizens”.

The chapters following in this thesis, in large part, venture to explore some of the ways in which the carrying on of living has embedded within it a kind of ordinary ethics, something that “[...] recognizes human finitude but also hope” (Lambek 2012: 4), and they draw on Lambek’s outline of ethics as an activity that is part of the social:

[...] ethics can be found [...] in the movement or tensions between the ostensible (manifest, explicit, conspicuous, declared, avowed, certain, normative, necessary) and the tacit (latent, implicit, ambiguous, subjective, aporetic, paradoxical, uncertain, transgressive, possible), and between the application of criteria and the recognition of their limits. [2012: 28]

In other words, the ethical is something emerging in familiar breaches of confidence and faith. Going back to Robbins’s (2013: 457) discussion of alternatives to suffering as basis for anthropological inquiry, this thesis attempts to follow suit in considering anthropologies of the good. Much of what I gleaned from my time in the support groups was that as a volunteer I was not there necessarily to bear witness to

the pain of others, but to show my empathy, and foremost, to enable participants to see the good that was possible even with a lifelong illness. In thinking about pursuits of the good alongside the management of insecurities and disappointments, I try to develop not so much how people saw the future, than ways of reconciling with the present.

London: methods, field work, blunders

London was chosen as a location in which to establish relevant field sites given its multicultural and epidemiological profile. My initial research plan was to look into how marginalised or stigmatised groups were positioned in debates about the containment of tuberculosis and HIV. A large proportion of new cases of TB and HIV remain concentrated in the country's capital.⁷ The city also had a dense circuit of advocacy, human rights and non-profit organisations responding to the wider issue of access to health care and social support amongst vulnerable persons struggling with homelessness, employment and/or other mental or physical health problems.⁸ Shortly after arriving and settling in late summer of 2010, and making contact with various third sector HIV and TB organisations focused on health promotion, I decided looking into the politics of epidemiology would take me down quite a different path from themes of belonging, migrancy and illness narrative – themes and

⁷ The Health Protection Agency (HPA) estimates that in 2011 there were 96,000 people with HIV in the UK. The UK HIV charity Terrence Higgins Trust (THT) approximates that a little over 41,000 were living with HIV in London. The HPA posits close to 9000 cases of TB reported in the UK in 2012. Public Health England's 2012 TB Annual Review for London, estimates 40 percent (around 3400) of cases were in the capital.

⁸ Many of these associations either worked under either a very broad set of mandates (such as the right to access the health service and register with a GP), or very specific and more extreme instances of cruel treatment (being detained, forced removal from the UK, denial of medical care in detention, for instance).

ideas that I was much more keen to develop, particularly after conducting trial interviews with former TB patients who had histories of homelessness.

The anthropology of London has been, and not without justification or provocative analysis, heavily drawn up and divided along lines of ethnicity and cultural community (Dench et al. 2006; Bauman 1996; cf. Napolitano 2007). Interest in migrant health is sometimes assumed to fall within these terms. Similarly, religious and faith based alliances and projects have received considerable attention, not least from community and public health technocrats interested in how these associations offer socially viable networks for encouraging healthy lifestyles and behavior. During field work I attended a number of community meetings in east London concerned with quality of medical and social care in the area as a whole, which had a history of higher than average levels of social deprivation. I met a variety of individuals working in different capacities: advice centre coordinators, advocacy trainees, community organisers, GPs, students, researchers and voluntary administration personnel. I spent three months as a volunteer at an advice centre for migrants. It was not formal research and the coordinator consented to my volunteering solely for getting insights into some of the general issues and experiences migrants they served were facing. It was a useful time that helped me think about how research terms and categories of “refugee” and “asylum seeker” were not always accurate, and perhaps functioned more as legal and discursive categories if anything (Good 2007). Only a small fraction of their visitors had been granted “refugee” status, and the rest had come to the UK for different reasons. It was also here where one of the visiting nurses gave me referrals to projects cutting across communities, pointing me to several HIV charities that were active and

worked directly with persons with HIV, as well as a mobile TB screening project that visited hostels and shelters throughout the city.

I found it difficult to resolve whether the number of charities servicing particular groups impacted by HIV were there because the condition was indeed a more serious problem, or if the problem was consolidated, and portrayed as such, in order to justify funding and the founding of new social initiatives. I suspected it was a bit of both. The coordinator of one relatively new mentoring initiative for HIV positive refugees and asylum seekers stressed the unique demands of this group, “For our service users a lot of things can come up, so we could be dealing with stress and anxiety as I mentioned before, or it could be depression, self harm and suicidal feelings, trauma, post traumatic stress, mental health problems [...]” I found, projects set up for persons with immigration problems expressed similar concerns. I make no claims to denying or playing down the maneuvering that might be integral to community and charity initiatives, it was clear a strategic essentialising, not so much of identities than of needs, played a role in their efforts to highlight the importance of their interventions, which were critical lifelines in many instances.

I tested the waters with the community mobile screening team briefly.⁹ Some of my conversations and observations from these encounters are brought out in various chapters. What I found most interesting and rewarding in reaching out to this team was meeting the individuals who were ex-TB patients, and now working as volunteers on the project to provide peer support. The team’s clientele struggled

⁹ At the time, it was funded by the civil service (not the National Health Service, nor were the staff NHS employees), which simplified ethical approval to a degree. (Any research done with NHS staff or on NHS premises put one in a different system and bureaucracy for attaining ethical clearance – this excludes “service evaluation research” attempting to collect data on patient satisfaction for the purposes of improving a service. In these cases ethical clearance can be arranged with a consultant and the hospital’s research department).

with homelessness and chronic health problems, not unlike many of my HIV informants. At the HIV charities a large proportion of attendees were black African, though it became apparent their concerns ran the gamut of frustrations related to lack of steady work, appropriate documents, and/or accommodation.¹⁰

I gained the most momentum through the HIV support groups and eventually grounded my field work in three groups run out of charities in different parts of London. For the purposes of confidentiality, I have in some instances melded conversations, scenes and characters, (or conversely, broken down or swapped them around), in order to create composite illustrations. I interviewed key staff members, along with a member of staff working in a charity more focused on policy and campaigning for the rights of HIV positive Africans in the UK. I also attended community HIV and chronic health events and workshops across the city. I signed up to be a volunteer at one of the larger HIV charities clarifying in my application that I was a PhD student looking into migrant health and chronic illness issues in London. After three months of volunteering, I requested from the program coordinator and service manager formal permission to do participant-observation research. The service manager stressed their policy of denying student research requests on principle, as they feared clients would get the wrong impression about the group's purpose, "That's not what they come here for, even if *one* person thinks that [that they are being approached too often for research/interviews], that's one too many. We manage that perception very carefully". They had all the reservations expected of a service dealing with vulnerable groups. But they also emphasised the

¹⁰ Most charities and monitoring agencies have been careful about how the virus is linked up with groups and their movement and settlement across different geographies. The National AIDS Trust points out the "determinants" of health that often put migrants at risk for infection, including, "[...] high risk of poverty and poor access to safer sex education and healthcare" (National AIDS Trust 2008).

helpfulness of my volunteering and appreciated the time and effort I had thus far invested to support their clients, as well as in working with the staff and other volunteers. They consented to observation research focused on understanding their principles, and the tools and instruments of self-management they provided to visitors. I was permitted to make general observations so long as no personal identities were revealed. I did not carry a notebook around but wrote down my thoughts shortly after the sessions ended.

I treated this charity, where I had the most routine exposure to a specific program and set of activities, along with interacting with clients and voluntary staff, as a site for collecting insights, instructions and ideas of positive thinking and instruction, and articulations of mind over body. As a program volunteer this involved engaging in a variety of tasks: facilitating group discussion, going through worksheets and questionnaires, helping in the kitchen with dinner service, moving tables and chairs, assisting people to their appointments in the different clinics happening around the centre, and chatting more generally with visitors.

Contesting colour

“African-ness” and “African community” were recurring terms and phrases that I had to negotiate through field work, and sometimes after. I recall presenting to a peer seminar a short piece on a group therapy. A colleague asked me, “Why not talk about the African-ness of the group? The intercultural dynamics?”

I was often uncomfortable whenever I used “African” to describe the people I met. I was aware of how freighted the term was, how synonymous it had become with a host of tragic situations and problems. I found troubling the consistent ways

in which any phenomena related to “African” was constituted as a problem, or, conversely, as an aesthetically rewarding, cultural Other (Wainaina 2005). There were also the emotionally pleasing aspects of the term tied to the humanitarian intentions in wanting to help and improve. I struggled with this during my research particularly because I did not want to feed any further into the naturalising of illness and disease as synonymous with a community or subset of population.

I have thus resisted casting this work as a matter of health issues amongst or within the “African community”. The programs and support group meetings I came across sometimes appeared to contradict their own aims. The coordinator of one group made a point near the end of our interview, saying how Africans only made up a small proportion of HIV positive diagnoses, (as well as only a fraction of international migration into the UK). Another project manager who had previously worked on HIV community care in Ghana, and was now running a volunteer buddy program for asylum seekers with HIV, said HIV was about everybody, it did not matter if one had HIV in Ghana or in London, “HIV doesn’t discriminate”. The dilemmas of phrasing were not unlike those I felt with illness and disease categories, the nature of their clarity and the issues and themes they indexed.

HIV is an equally freighted term. Other questions and comments in response to my observations at support group meetings circled around the management of stigma, discrimination or sexuality amongst minority groups. But it was not unusual, and perhaps even expected, to have a trajectory in which diagnosis was told, received and reconciled. I had to consider as well the misfortune of illness at the point of its normalisation. I noted a significant temporal dimension to these recollections, that the pain and injury of these experiences could be reiterated and reflected on not only

as traumas belonging to the past, but significantly, as an event embedded within a broader series of events, journeys and incidents. These individuals were identifiable to me initially as people living with the virus though that was not what kept me attached to them.

The question as to how and why HIV was made a part of this study still puzzles me occasionally. It was a means through which I accessed people that eventually became my informants and acquaintances, but they were also people that I could have met in other ways and through non-HIV related sites. In which case, their HIV status would probably have remained undisclosed to me and I would simply know them as person x, y and z, dealing with situation x, y and z. Sense of place, identity and welfare would probably have emerged in a similar fashion, as they tend to do in almost any conversation about moving to and in a new place, and negotiating legal, administrative and cultural quagmire. Did knowing their HIV status really radically change and orient what I came to know and understand, and what I have in the end written about? Might I have substituted HIV with some other condition, or scratched it out altogether, and nonetheless come to similar conclusions? I hope to show throughout the thesis the ambivalent and fragile positionings of a condition such as HIV, and a way of thinking about people first as human beings (without romanticising a universal humanity); and that the classifications filing in after that, “African”, “immigrant”, “HIV”, will be reflected on critically for what that they sometimes impose on others (Hacking 1999).

Field sites in motion

The support groups were challenging locations from which to anchor my field work, given how they really only operated within a given time slot and space. I came to appreciate these groups and charities as kinds of community centres. These were locations where people came together with an understanding of one thing they would likely all have in common. But they also gathered to speak about other things besides being sick, had different concerns and aspirations. How such environments constituted particular communities of mood equally struck me. That is, zones and spaces where sentiments were pooled, articulated, and/or reframed in new ways (Muehlebach 2011). The desperateness or near desperateness of visitors was highlighted by one support worker who stressed the compromise that takes place between giving and limiting care due to eligibility:

Somebody who doesn't have recourse to public funds, they're not supposed to be helped, but at the same time, for many people who are HIV positive, and who are under immigration rules, they are still accessing social services. Somebody seeking asylum, and the grounds of health, still need to be accounted for, but immigration rules said you're not supposed – to go as far – as they don't even have to get medical attention. But we've also got now the human rights coming in... there's been some kind of compromise between what the strict British laws are saying, and also what is humanitarian. And also, how are you going to control... if you are applying for asylum based on health – ok, not asylum – but applied to stay in this country based on health, and then also, if it's an illness which has to do with public health, how do you manage it? And they are still human, they'll need to be alive, they'll need to carry on with their life, maybe social life, and things like that. So that's why it's quite complicated.

These broader political circumstances were often marginalised in the meetings in favor of subjects more specifically about “health”. Feelings and emotions were carefully managed at these sites. I found them sometimes to be social equivalents of “antidepressants” in how they were fashioned as complementary to

the pharmaceuticals their clients were taking. The circulation of representations of suffering and pain are oft noted as central to the staging of humanitarian advocacy, but many have pointed out that a consideration of affect, as a noun and transitive verb, brings other questions into view about the politics of good and bad feeling, be it happiness, fear or love (Ahmed 2004, 2008); continuums between desire and reason, and the unpredictable conjecture between the “power to act and the power to be affected” (Negri and Hardt 1999: 85).

I was not the one to be supported or empowered, but the exposure to repetition and reiteration gave me a sense of how certain sets of procedures and advice, even spirited ones, become routine. The time spent in these spaces were important for gaining insights into the performance of illness management as something that is integrated into the everyday, and further they were useful windows into how hope, and not only an illness identity, are constituted as sociality. My hovering along at a low level of constant disorientation, the exasperation I sometimes felt with many of these group meetings, the occasionally gently patronising tone some sessions would take, and the seeming redundancy of some of the instruction delivered, I felt to a degree mimicked the frustration of participants. Most people appeared to enjoy the sessions and the company they came with, but indeed, it was only in having further conversations and encounters with individuals outside the meetings that I built a deeper appreciation, both for what such meetings offered and demonstrated, and for the ways in which they were sometimes collective symptoms of individual situations of distress (Biehl and Moran-Thomas 2009).

Field work in large city was at once overwhelming and underwhelming. It often felt erratic and short-circuited. One of my most treasured artefacts from field

work was a small day planner I purchased from Ryman¹¹ in Holborn a couple of months after starting out. It measured no more than fifteen by ten centimetres, and had a black, matte leather cover. There were clear plastic sleeves in the front and back where you could tuck in small notes or business cards. I often flip through it, not necessarily for field notes, (although sometimes I wrote in it if I had forgotten to take a notebook with me), but to remind myself of the variety of days when nothing really happened (June 20, add credit to phone at Belsize Park, buy toothpaste), and when things did happen (June 25, 10:30, meet U. at London Bridge near footbridge). Often what brings me back the most are the endless miniature maps and directions I scrawled out for myself: Taking bus 343 going toward City Hall; bus outside Morrison's, 329, 121, 232, drop off Berkshire Gardens. The sites and informants I grew to be familiar with were in their respective locations, but they also cut across the city's boroughs. In some ways I ended up maintaining my position as an outsider. There was also perhaps something artificial about my expectations of intimacy and friendliness when attempting field work in a large urban centre, where distance and alienation are in some ways the means through which people live together.

Key participants

My collated sample was kept within modest bounds. In the course of my field work, knowing more about a few people seemed something to be relished. I concentrated on fostering the trust of key informants, being steadfast in reaching out and making contact with them, rather than stacking interview upon interview.

¹¹ A British chain of stationary shops selling office supplies.

The majority of my informants were recruited through a second charity. It was here that I connected with the voices whose narratives and musings would eventually shape much of what I took away from field work. After consultation with the support group leader and charity manager, recruitment was done at one of the meetings. I made an open call for interviewees, reiterating confidentiality and protection of identities, inviting participants who had pending immigration cases and/or no residency applications at all. I received interest from some people who had recently been granted permission to stay in the UK, and agreed to include them in my sample after being advised that many attendees were still struggling with the same issues. This also gave me occasion to reflect on the ambivalence of these categories and stages of passage through legal systems (Rotter 2010).

In reaching out to people through the door of a particular condition, I was keen to know more about the renderings, articulations and emotions around the illness, I wanted to know what was involved in these collectives of support and positive thinking. I also knew the meaning and resonance were dependent on the nature of their audience. The profile and identities of the people I came to know could have been very different had I contacted other organisations, for instance, either along lines of religion and faith, sexuality or race. That immigration and homelessness were some of the primary difficulties, and that many of them were African, was something of an accidental meeting, although it was not surprising that people struggling with economic and legal pressures were part of an ethnic minority and sought out services across sectors and boroughs.

Often it was after the formal interview was completed that relationships and rapport were built. I spoke with nine individuals, all women, with one exception, in

their late thirties, early forties and fifties. I accompanied them on bus journeys, met with some in parks, for Sunday church, window browsing, and the occasional coffee. Other times I relied on telephone conversations, text and email (for those that had email accounts) to stay in touch.

Dramatis personae of key people who will figure in the thesis (in alphabetical order):

Dennis, born in the UK, mixed heritage of British and South Asian ethnicities, ex-TB patient

Esther, from Nigeria, application for leave to remain pending

Eugenia, from Zambia, application for leave to remain pending

Mary, from Uganda, application for leave to remain pending

Nancy, from Nigeria, without travel documents or any immigration applications

Regina, from Botswana, without travel documents or any immigration applications

Ruth, from Uganda, has indefinite leave to remain

Sandra, from Uganda, has indefinite leave to remain, ex-TB patient

Tabitha, from Malawi, application for leave to remain pending, ex-TB patient

The nine informants noted above are those that I developed stronger relationships with.¹² They agreed to interviews as well as speaking and meeting outside support group locations. My informants were largely from sub-Saharan Africa. Our conversations were held in English with few problems. However, I spoke also with a wide number of individuals on a casual basis within the groups. These women and men came from a variety of countries and backgrounds including: Switzerland, Northern Ireland, Italy, Zimbabwe, Kenya, Congo, and Egypt. I considered them, if not informants, then acquaintances and contacts who not only contributed to my awareness and knowledge of what living mutually with chronic disease and socioeconomic vulnerability entailed, but obviously enlivened and

¹² All names and some identifying details have been changed throughout the thesis to protect anonymity.

coloured these spaces with their speech, movements, conversations and interactions – fragments, scenes and instances that have been woven through my ethnography.

My informants, and others that I met who attended the groups, lived in different boroughs of London. Support group staff approximated that most of their clients were from the boroughs of Enfield, Haringey, Hackney, Newham, and Lewisham. Based on staff estimates, around sixty per cent were residing in the UK with pending immigration applications, but it was unknown to them how many exactly were living here undocumented without any applications to the Home Office at all. Both those who had and had not received their permission to stay in the UK received varying levels of support from their local councils. Cases appeared to be dealt with individually, depending on both their local council and social care offered via their clinician. Informants shared similar immigration situations but some had success in securing transportation support or accommodation for example. Some of my informants had residency documents but no work or council housing. Others were without residency papers but were able to get help, often from social care workers, with securing council flats. Of the nine individuals noted, four were living in flats sourced and subsidised by their local council authorities. The rest were in private rented accommodation or staying informally with friends and/or partners.

Nearly all, regardless of immigration status, were job seeking and/or looking for ways to supplement their incomes. The kinds of work mentioned the most to me were: caregiving (mostly of elderly), cleaning and maintenance jobs, volunteering with churches and charities. Previous jobs held before becoming sick included: caregiving and looking after their children and families; one used to work as a nurse in her home country; several others mentioned running small businesses in the past,

selling and trading goods such as cosmetics and handmade crafts. About a third of individuals I spoke to, had their journeys facilitated by family and grown children already living in the UK, and the rest were helped by acquaintances, almost all spoke of arriving as tourists, with one saying she came to London as a student.

I have invested in individual biographies but my claims to an intimate knowledge of another's existence remain deeply cautious. My choices were in part influenced by methodological constraints: the difficulties of establishing clearly defined communities in as populous and diverse a city such as London, the limited number of fixed sites and areas where I was able to meet informants and have regular contact with them. It was impossible for me to completely "follow" people. I had to be purposeful in reaching out to individuals and arranging times and places to speak. But there is little that is "natural" about field work, be it in an urban or rural area. In the course of field work it became clear to me that the lives I came to know refracted something about how the ethnographic forms we generate are co-constructed objects – with our informants, and with our field work milieus.

Significance and contributions

The thesis makes a number of interdisciplinary contributions to studies of chronic illness, chronicity, HIV, ordinary ethics, migration and the anthropology of London. It brings together subjects of migration and HIV in novel ways. In drawing attention to the accidental converging of HIV, pharmaceuticals and migration, it highlights the unpredictable forms in which citizenship claims take shape, and go adrift. It elucidates how the basis for social entry, as well as exclusion, is deeply troubled. That is, being sick with HIV initiates one into systems of care offered by

hospitals and charities, and further services for some, without resolving the legal and political-economic barriers to employment and self-sufficiency.

For scholars and practitioners working within areas of community and public health, this study adds to research on both the continued importance and limitations of support groups for HIV and chronic illness management. Support groups and charities continually evolve in hopes of better serving their visitors. In speaking to the fragilities of biosociality, I am not suggesting groups assembling under the rubric of illness serve little purpose. On the contrary, this thesis illustrates how multifaceted support groups are, in the activities and conversation that unfold, and how this diversity is also a matter of recognising the diversity of individuals and collectives within them. The thesis contributes to ethnographies of HIV in terms of chronic illness and chronicity over infectious disease, by focusing less on the integration and presence of HIV into everyday routine, than its lapsing into a wider ethos of wellness and optimism, common hardships and distractions. In considering not only how individuals suffer but also how they endure, this work contributes to the emerging body of scholarship on ordinary ethics, and the extent to which the pursuit of good is stitched into both everyday and extraordinary events and negotiations.

This thesis adds to the anthropology and ethnography of London. It builds on existing work emphasising the cultural complexity and identities that make the city, its dimensions of refuge and alienation. The thesis also speaks frankly to the difficulties of establishing familiarity and relations in a busy urban centre, and the significance of field work that takes place in between places, such as on mobile

phones, walks and bus rides. As such, the thesis makes methodological contributions to the trials, novelties, and prosaic gestures of field work in a city.

Structure and summary of chapters

The dissertation is structured in six chapters, they are ordered in part to reflect the trajectory through which I came to know my informants and their concerns, and they rest in a slightly parallel fashion to convey how informants and I returned to and revisited certain topics. The ethnography has been shaped largely along the lines of snapshots of scenes and activities, and developing portraits of informants (Biehl 2005). The aim has been to communicate the fine line between field work and informants as wholly different cultural experiences one would not have otherwise had, and as experiences and encounters that grow out of familiar localities and movements.

Chapter one, “How the mundane matters: group therapy and grievance” looks at a charity working more broadly in chronic illness management and support. It focuses particularly on the eroding of senses of crisis and exceptionalism through pedagogies of self-care, premised on everyday living and habits. Drawing from observations made at this support group, founded for persons of ethnic minority background, I want to allow for the possibility of bringing out the comical and superficial as dimensions of both burden and relief. It sketches out the various topics and themes visitors were encouraged to be knowledgeable about: goal setting, nutrition, professional development and mental health. Interspersed with these descriptions are observations of some of the social dynamics, tensions and humour within the group. The chapter reflects on how self-care education and training can

take apolitical and slightly farcical forms, and suggests there is comfort in their inadequacy, in helping by not helping. It attempts to provide an alternative to social suffering as the primary critical prism through which to authenticate HIV.

Chapter two, “Chronicity” attempts a wider discussion of the metaphysics of chronicity and what it means to experience time and living as extended periods of stasis, although significantly marked by events of misfortune. My entry into this thematic and issue is through three ethnographic examples that highlighted being and living as a kind of chronic condition itself. It peers into the reflections of an ex-TB patient, the lingering of thoughts and experiences of previous streets and places that used to be his home; and the narratives of two women from Nigeria who both have HIV and are troubled by uncertain citizenship.

Chapter three, “Unsettled bodies: between home and homelessness” focuses on sense of place. It argues the mundane inhabiting of city spaces is critical for exploring dimensions of being chronically unsettled. The chapter explores different ways, moments and dimensions of being homeless and feeling distanced from a particular place. It looks at how the “in-betweeness” individuals felt, more often than not, spoke to conflicted sentiments about their present inhabiting and dwelling. It illustrates with examples drawn from conversations, excursions, and movements through the city with informants. The chapter draws attention to configurations of the homely and unhomely in varied spaces of the city: their emergence in incidents of interrupted accommodation, a photography exhibition, public transportation, and walking. It situates distraction and grievance, laying out in further detail the ambivalence and disappointments experienced by informants attempting to find consolation and footing in London.

Chapter four, “Objects of emotion: making therapeutic feelings” explores more in-depth how feelings and emotions become key terms and mediums through which therapeutic intervention is rendered. It looks at the work of a charity devoted to supporting HIV with a very distinct spirit of optimism and cheerfulness. I give examples of the centre’s key workshops and demonstrations on love and relationships, the management of difficult emotions, and relaxation therapy. I discuss how feelings are rendered an object of instruction and intimately tied to valuations of the self. Positive thinking may not appear to have much to do with love per se, but in the case of this social setting and organisation, I take up love as a wider thematic of speaking and doing in the affirmative.

Chapter five, “‘We live in a Barbie world’: self-fashioning, intimacy and performance” is a life history of one of my closest informants. This chapter elucidates the multifaceted ways in which self-care is put into motion in even the most precarious of circumstances, and how and why such efforts are worth reflecting on with the least amount of cynicism possible. This informant was unique in that she demonstrated particular investments in her personal relationship and appearance, and the chapter looks particularly at her interests in fashion, trials and infatuations with her partner, all of which had disconcerting underpinnings related to her legal vulnerabilities. The chapter aims to show through an in-depth case how care for one’s self is compelling for what it reveals about definitions and claims about what is good (and not good) for one’s self and body, and that there are complex relations and commentaries embedded within about responsibilities between people, the usefulness of objects and things, and the significance of jokes and laughter for staying resilient.

Chapter six, “Second chances and ordinary thresholds” takes up more closely the question of a second chance and how informants reflected on their second chance whilst occupying “life and death” positions in Britain. What may be presented as a shrinking of humanity into an essence of biological matter, might instead be explored as effects; enacted, repeated and believed, things that are accomplished, made tangible through acts (Butler 1999:181). The chapter discusses the undeniable medical grounds for being in London and how interjections of “being alive” were sometimes conjured as consolation, rather than a right or necessarily joyful celebration.

Chapter 1

How the mundane matters: group therapy and grievance

In her well-known essay *Illness as Metaphor*, Susan Sontag (1989) proposes exposing the violence of metaphors that can exacerbate experiences of illness, and often make patients culpable for their condition. But she also makes another observation near the end of her argument that might pose an equally challenging proposition. She writes, “That even an apocalypse can be made to seem part of the ordinary horizon of expectation constitutes an unparalleled violence that is being done to our sense of reality, to our humanity. But it is highly desirable for a specific dreaded illness to come to seem ordinary” (Sontag 1989:181). It is a difficult set of statements to reconcile: for something to be violent, and desirable that it should be seen as ordinary.

How might we take up Sontag’s remark as an exploration into illness becoming “emptied” – emptied of passion, alarm and spectatorship? Relatively early in my field work, I was struck by how diseases of seeming public health urgency – for their potential to spread, to be contracted – were given the impression of being well contained, often with discourse and rhetoric: reports, plans, suggestions, pamphlets, leaflets, posters, and charts. Containment supported through discursive and paper borders. Might we add petty control to these inquiries into institutional regulation and self-care?

This chapter explores how interpretations of what we might consider to be shared affliction could be cut through with distraction, irritation and idleness. In thinking about the group’s chemistry and cohesion, I try to work through what was represented to people, the effort to shift from a sensibility of desperation and despair

to capability, and how the containing of illness is a step to ordinary life. In speaking to the challenge and limits of biosociality, the chapter also points out how such aspects can be good things for people, in giving them a chance to articulate frustrations, and to complain. Getting dressed and attending something that was voluntary suggested an element of participating in something ordinary. The “catalysts for chronification” that van Dongan and Reis (2001) speak of, as both technocratic and social catalysts perhaps, can partly be seen not only in the norms and pedagogies of what self-help groups promoted, but in the act of being a part of something where other topics and concerns collided with HIV as the primary focus. The chapter’s plain, almost understated, presentation of ethnography is in part a writing strategy and a mirror of my argument. They resist clear themes and I try to communicate something about how self and illness management, and of commiserating together, are jumbled ventures.

Advertising improvement

After fieldwork, I kept close to me a wide brown unmarked envelope, which was filled with paper, odds and ends collected during my time in the field: leaflets, reports from events, newsletters, and newspaper clipping. I stumbled across two pieces of paper randomly during my first attempts to write this chapter. I had turned the envelope upside down one afternoon to empty its contents, and they fell out lying side-by-side. I recalled then the afternoon I visited Healthy Connection, an HIV and chronic illness support group that a community nurse had suggested I get in touch with.

I had arrived early and was sitting in one of the folding chairs off to the side closest to the windows. Another round of chairs were set up around two tables pushed together in the middle of the room. One of the clients was walking around the table, putting leaflets in each spot. I leaned forward to grab one and saw it was an advertisement for an event near Canning Town train station in east London. In the upper left hand corner, printed in simple, medium sized print, “Guaranteed Deliverance & Endless Happiness”, and in the page’s centre, in three different fonts and colors, “FIRST Women DELIVERANCE in UK”. The date, time, location and transport information were listed below. The very bottom of the leaflet was trimmed with a red border and printed in lower case letters, “moving yourself out of misfortune through prayers.”

I looked a little more closely and saw a small logo at the bottom right hand corner: a red circular frame enclosing a drawing of a flame with a black silhouette of mountain peaks in front, curved around the top were the words, “Mountain of Fire and Miracles” and at the bottom in the middle, “Ministries”. The main picture taking up the top half of the leaflet was of a woman’s head tipped back slightly, presumably in exaltation. She was of a fair complexion with brown hair, her eyes were closed, her chin was pointing upward, her mouth open as if she were singing and a chord was sailing out, her hands were raised up with the palms outstretched.

The second leaflet was one that had been placed on my chair when I arrived. It was a print out of two National Vocational Qualification (NVQ)¹³ programs. One was for “Customer Service” and another for “Business and Administration”. “Edexcel: advancing learning, changing lives” was the name and tagline printed in

¹³ A work-based accreditation earned on the job recognised in England, Wales and Northern Ireland.

the upper right hand corner. The customer service program featured a lady wearing a headset, looking at a computer screen, her face apparently in mid speech. The business and administration offering showed four people sitting around a table, clearly in the middle of a meeting, a gentleman in a blue shirt with a laptop opened in front of him appeared to be leading the meeting, files and cups of coffee are scattered in front of the others.

I looked at the two leaflets for a few moments and wondered if their unrelatedness said something about the comedies and tragedies of the group and its dynamics; and of the vast stretch between what was really doable and what was conceivable, beneficial and desirable for each of the individuals attending. The group's coordinator, Diane, called it a "therapeutic group." "Getting back into work," "skilling up," "training," were often reiterated as the only viable long-term solutions out of clients' financial limitations. And at the same time, there was another set of scripts and feelings brought in to the scene. It was clear, the sense of carrying out the motions and requisites of a community and peer support activity. The help and care was also mired in clients' concerns about how they were being compensated for their time and attendance. There was considerable annoyance and upset over travel money – background chats that some individuals were given extra money for setting up beforehand and tidying afterward; along with worries about how much food there was for the meal and how much extra left to take home.

The two leaflets noted above spoke to ideas of the miraculous and the mundane, of transcending present trials, and of being firmly placed within them as someone with skills and expertise. The activities of the group were obviously positioned in the latter, but what was fascinating to me was the ways the trivial was

enmeshed with, as well as symptomatic of, extraordinary struggles. The things people will do and try to have a little more hope in their lives is not an unusual theme in medical anthropology (Kleinman 1997; Nguyen 2005). What I want to spotlight here is how we might think about seemingly petty activities and motions as an element of group therapy, and as a means of being alone together.

Healthy Connection

The HIV management group Healthy Connection was one of the programs offered by Wellspring, a community health charity in London. From the charity's brochure¹⁴: "We are a voluntary organisation that provides services and education to individuals living in London, about living well and how to manage long term conditions. Wellspring offers help and support to those suffering from diabetes schizophrenia, HIV, depression and those seeking healthier lives". On its activities for persons with HIV, under the heading "Peer Support Teams," it states the following: "Offering peer and emotional support to BME [Black, Minority, Ethnic] communities diagnosed with HIV in order to reduce isolation and stigma associated with HIV. In addition, signposting clients to services from other appropriate institutions depending on their needs".

Diane, the meeting's leader and coordinator, informed me Healthy Connection was open to persons of any race and sexuality. She said the group was different in that it was "culturally sensitive". This was when she went on to say that groups for people with HIV were previously mostly for men from the gay community. It was not entirely clear what was distinctive about the group's purpose

¹⁴ Not quoted word for word – some word and phrasing changes were made to protect anonymity.

other than that it was aimed at people who were not white and not gay. But this group was attended ninety five percent of the time by people from African countries.

Nearly everyone attending had an immigration application in progress and did not have the right to work; or, they had recently been given permission to stay in the country, but still needed help becoming independent. The peer leader told me that many clients had sustained long periods, years often, filled with little else than waiting, and thus lacked “confidence” and “skills”. There were some though, she said, that stopped coming to the group and began new plans after being granted leave to remain, dropping in only to say hello to old friends once in a while. Those who had been granted legal status and still attended usually kept coming for a variety of reasons: some were above the age of fifty five, in poor health, unable to work full time hours, and/or still looking for employment.

I maintained an observer role at this field site. I did a brief audio interview with the team leader but most of my insights took shape through informal conversation with visitors during and after meetings. My initial sense of this group was that it was as composed and poised as it was tired. To an outsider peering in, it was simply a room full of people with darker complexions. I can recall at the start of one session, we were on the ground floor and one of the big windows was pushed all the way up so you could easily stick your head through from the outside. Two teenaged boys wearing jeans and bouncing basket balls passed by and one pointed and nudged his friend, “What’s going on there?!” One of the clients closest to the window turned around, smiled and whispered loudly to them, “We’re having a meeting! It’s a meeting!” A puzzled expression came over the boys face for a

moment; his friend punched his shoulder and said, “Come on, let’s go”. No one else in the room took much notice, said anything, or bothered to draw down the blinds.

The meetings were held once every three or four weeks, depending on peer leaders’ availability, and the expected attendance. There were anywhere between ten and twenty individuals each visit, and more women than men, between the ages of forty and fifty-five; there were a few visitors in their thirties, and above fifty five years.

The sessions were held in a small fading grey building that had bits of leggy buddleia and crumpled ferns sprouting out from odd corners and patches. A large Tesco¹⁵ shopping centre was nearby. A busy central road ran along outside. Most of the neighbourhood space appeared to be taken up by a matrix of streets, confusing pedestrian crossings of differently sized, unevenly spaced islands, unusual roundabouts, and parking lots. Flyers advertising a ghost and heritage tour of a major local cemetery were regularly stuck to the community notice boards. The facility was clearly embedded in the neighbourhood and had nothing peculiar about it. The team leader mentioned that when the organisation was initially being founded, there were disputes about its location. Some funders thought it should be in a predominantly “black” area. However, in the end, a mixed, but largely “white” borough was settled on. Diane said it had turned out for the best because a lot of their clients preferred to attend the session outside of the borough they lived in.

¹⁵ A large supermarket chain in the UK.

Intersections of ordinary and extraordinary situations

The function of illness support groups has typically been highlighted as key sites for learning about the management of one's condition, and finding and comfort in meeting others in a similar situation (Ussher et al. 2006; Coreil et al. 2004). Therapy is given a connotation beyond biomedical or physical confines, emphasising feelings of relief and camaraderie. But the sense of exclusiveness for entry into a group does not imply that such interactions are categorically different from other social or group activities for which there is a shared concern. Prince and Marsland (2012) have looked at the ways HIV becomes a channel for seeking and maintaining voluntary and paid work, and networking more generally. In her study of support groups for persons with bipolar disorder, Martin (2007) notes participants' and facilitator's routine engagement with one another – exchanging experiences, mutual problems, and solutions. She writes, "In almost all support group meetings, to a greater or lesser extent, *people create new social connections that last over time*" (Martin 2007: 143, emphasis in original). This aspect however was not something easily gleaned from the groups I worked with. Further, anthropologists have highlighted how deeply conflicted and novel support groups and collectives can be, in the emotions and attitudes people enter with, their responses to fellow attendees or the group's ethos, and their social aims (Klaits 2009; Irving 2010; Le Marcais and Inggs 2004; Rhine 2009).

Healthy Connection was performed and run as a kind of solidarity group, but as I became more familiar with it and its visitors, I learned the bonds were much more brittle. Peer leaders gave presentations and advice during meetings but appeared to switch off at the end afterward. Clients exchanged mobile numbers with

each other, yet some told me this was simply to ease the gathering of information. Keeping track of opportunities and activities, I would learn, meant some weeks the size of the group swelled compared with other weeks.. I remember on one occasion there were as many as twenty-five people crowded around the table. I asked one visitor where all these new faces came from, and she said they had heard there was interview recruitment happening for a local research project about “discordant”¹⁶ couples of east African heritage in London,. Word had gotten around that there was twenty pounds compensation for participation. She chuckled a little, “I bet some people were mad when they found out it was just for people from east Africa!”

This chapter explores how everyday self-management pedagogies and illustrations are entwined with what are also spectacular and extraordinary trials. Anthropologists have highlighted “the everyday” as a crucial aspect of individual and collective living just as worthy of attention as elaborate rituals or political demonstrations (Seremetakis 1996; Green 1998; Napolitano 2007). As most of the material here was gleaned from the meetings themselves, I want to consider renderings or projections of what people can or should do in their everyday.

The meetings and topics appeared to be “performances” given by the facilitator or presenter with the aid of audience members as both spectators and participants, but they were also seemed to me an interweaving of both ordinary and extraordinary situations. There was the mundanity of the group, as not being a particularly exciting site of decision-making or political capacity. This seemingly near redundancy I suggest is just as provocative for getting a sense of the rhythm and pace many of these attendees were experiencing in their efforts to make a living

¹⁶ Couples where one partner was HIV positive and the other negative.

(Marsland and Prince 2012) - their efforts to simply keep going and maintain a semblance of momentum.

The sessions

I start by sketching out scenes related to diet, information and psyche, topics of travel money, food, and renderings of benefit and policies. The point is to use encounters and incidents involving sustenance and mood to shore up reflections about what they might say about isolations of grief and frustration: as a social formation, wherein individuals are held apart, but within the same embrace. I want to try to follow through with Sontag's (1989: 181) remark about tragic illnesses attaining ordinariness by considering what might be thought of as quite trivial pursuits in light of having HIV.

Setting goals

At one meeting, the facilitator stressed the importance of goals: "Set goals, but also action plan, go back to it and see what was and wasn't accomplished, why didn't something work out. We've talked about how important it is to set goals." Remarks were exchanged about food and food shopping. Diane said, "No one knows your body better than you. You should eat protein, your medication won't work if you just eat vegetables." A number of clients were subsisting on vouchers they received from charities. A visitor said she struggled with her shopping because healthier foods cost more and her twenty pounds did not stretch very far. Another client, a middle aged lady, who I noticed was always quick to respond and give suggestions, (with the same amount of self assurance, if not more, than the team

leaders), said from across the room, “I suggest you go sign up with Food Chain or a health trainer, they can help you draw up a budget and foods that suit you and your budget. It’s all about empowering yourself.”

One woman was deeply unhappy with her flatshare. She was on the waiting list for her own flat and had been allocated shared accommodation by the council in the meanwhile. She was convinced her flatmates talked about her behind her back. “How should I react?” she asks the group. Don’t respond, people were saying, you’ll just be encouraging them, play some music, go out, talk to your friends, do some shopping, to take your mind off it. She did not say anything for a moment, “You know one day I was having a seizure and all they could say was, oh the witch has gone down.”

One attendee spoke of a friend’s experience, “Her General Practitioner (GP) never listens to her. He is already writing prescription in the first moment. I went with her one day, said he needs to listen to her, ‘Make 5 minutes for her’, GP asks, ‘Who are you?!’ I say, ‘a support worker from THT.’ Right away he sits back and listens, says he does know the patient, knows what medication they’re on.” She said her friend went again on her own and this GP complained about her complaining and said they no longer wanted her as a patient.

A gentleman in the back wearing a large blue cap says he is being pushed between his HIV consultant and GP for a letter he needs for a housing application he was making.

Diane asks everyone to stay calm. She says, “When it comes to dealing with health professionals, as a peer worker, I’ve learned from personal experience, it’s

important to look them in the eye. In African culture, looking down is sign of respect, but here, you need to look them in the eye.”

One lady, Judith, comments that she is feeling low since her son and daughter in law (both school teachers) have moved to Sweden with their two young daughters. I asked if she had other family in London. She has a niece and another son, “But it’s not the same.” She said she had been back in Zambia for four weeks in June. “What was the best part?” I asked. She replied, “Oh, walking through to old places, the church I went to, the shops, new shops, old shops... now there is food. When I left there was no food, now there is food, there is food, but so long as you can pay.” I asked, “How did you feel there?” Judith let out a small sigh, “Well, a lot of my old friends, they look very old, even though they are the same age as me! I felt more flexible there.” Judith said she has not had a break since being off college, and has been helping with son’s move, and he has left some things in her flat. She mentioned that she did finally pass her English test, “now I want do maths.”

Another client, Donna, said she was late because she was doing outreach in south London, distributing leaflets, “They give small reimbursement, not much, but at least it’s something,” she says and smiles.

There is a new face in the group. She is currently job seeking. Someone asks her, “What kind of work are you looking for? To be a support worker? To work for the NHS?” She shrugs and says, “No, charity or some other agency, maybe care work... I’m sending out applications but... nothing. It’s a lot of work... not finding anything though, but... I can’t stay home.” Another client I had become friendly with, Linda, seemed irritated. She was colorfully dressed as usual, wearing bright yellow pants and jumper, a black hat and big silver earrings. I asked her how her son

is. She says, not great. After a moment's pause, she says she is annoyed that she does not have Freeview¹⁷ any more. I asked if there were other channels she could watch. "There are five, but they are boring," she shook her chin, shrugged, called out over the table to Sandra to get her a bottle of water before they're all gone, "I need to take my medication!" Sandra shakes her head and says, "There's none left." Linda says, "I can't believe it," and shakes her head. I asked about how the case [applying for leave to remain] is going. She shrugs again and tells me the law firm she was with closed down. They have given her a new lawyer but there have been no new letters from the Home Office. She shrugs again, looks down at her hands, which hold a ring on each finger.

The food comes in and several people turn their heads to look at the caterers coming through the door. Diane and Nelson had not finished speaking, though. Nelson said, "Everyone, we received some feedback recently that some people here feel the group is only for people from certain countries. That is not true in any way. We are open to people of any race, nationality and ethnicity." The outspoken lady who reminded the client about empowering herself, commented that some people are naturally quiet, some do not talk, and some are newly diagnosed, but, "It's our job to make them welcome, this is about bonding." Diane nodded, "That is right, we are all here to support one another."

Monthly supplements

One visitor I met said she always rinsed the cups in her office's kitchen a couple of times with boiling hot water before using them. She laughed a little and

¹⁷ The UK's free-to-view digital television service.

said it might seem crazy, “But you don’t know what germs are there.” The topic of water was one of the first presentations I sat in on at Healthy Connection. That evening’s presentation was actually meant to be on nutrition more generally, but the majority of the conversation came to rest on water. Diane was sitting in a folding chair at the front of the room, a laptop set up in front of her. She asked the group, “How many of you drink bottled water, how many from the tap, and how many boil the tap water and then let it cool?”

She continued, “The best thing to do is boil your water and allow it to cool. That’s what I do.” One lady put her hand up and asked, “But aren’t you boiling out all the minerals and nutrients?” Another put up her hand and said she preferred bottled water, “You know that way that it’s fresh.” The peer worker shook her head, “The label on the bottled water is just a label, it doesn’t actually come from a spring. They get the water from the same place that tap water comes from; they only repackage it, it’s only a marketing tool.” There were looks of impatience going around the room until one gentleman dressed in a light brown trouser suit stood up and asked for a show of hands – of those that drank bottled, and those that drank tap or tap water boiled. He nodded and said, “Ok, then *stick* with it” and sat back down. The room was quiet for a second. The presenter asked if there were further questions, a few shook their heads and she went on to the next slide.

Diane continued to discuss the importance of eating at least five servings of fresh fruits and vegetables each day. She suggested that if people could not manage to have fresh then frozen was a good alternative. One woman to the left with a bright green scarf wrapped around her neck raised her hand and said she thought those foods were “processed,” and was it not bad to eat too many processed foods?. A

small wave of nods went around the room. The team leader briefly put her hand in the air, “Everybody, processed foods usually means that they are pre-cooked and a lot of extra salt and sugar have been added to them. The frozen vegetables you see in the supermarket, they are only washed and cooked and frozen in that way, that is all. They have been processed, but only [in] this way.” The same lady responded, “So the frozen has the same vitamins as fresh?” The leader nodded, “That’s correct, madam.”

The doorbell rang – it was the catering asking to be let in. Within a few minutes the tables in the back of the room were full with large serving trays. The smell of a rich meat curry filled the air. A few clients rose to help the caterer. Cartons of apple and orange juice were opened and poured into plastic cups, which were passed down the table. Each person also received two small yogurt cups, along with a few pieces of fruit: clementines, bananas and apples. A queue started as people went to collect paper plates of stew, rice, mixed cooked vegetables and salad. The team leader told me to get in line if I wanted to eat something, otherwise there would not be any left. She then went upstairs to make photocopies of the presentation.

After people finished eating, bins and bin bags were brought out and some clients began to tidy up – wiping off the tables and brushing off grains of rice, tossing cups and plates away, sweeping the carpet, folding and stacking tables and chairs. The caterer had packed up his equipment. All the stew was gone with only a small amount of rice and salad left over. A number of clients had plastic containers with them and were busy spooning the rice and salad into their boxes.

The team leader was still nowhere to be found. Another queue was forming now, just outside the meeting room, by a small secretary's office near the entrance. The door was closed and you could see through the little window that Diane was sitting at the desk and clients were seated opposite her. One person said to me that they were lining up to get their travel reimbursed. The door opened and eventually a small crowd of people clutching five pound notes in their hands formed around the exit, chatting and saying goodbye to one another.

Meal preparation

Learning what to consume, what to put into your body and what to keep out of it, were regular topics and concerns. Food and diet were one of the more amenable topics through which to encourage self-improvement. Unlike questions related to standing up to a dismissive GP or making repeated calls to solicitors about an immigration application, the kind of cooking fat used, or sweetener one put in tea, appeared to rest in individual hands, shopping carts, and cupboards. "It all comes down to you," as Nelson would say.

One week the HIV charity Meals for Life came in to do a demonstration. It was led by a group of three, two men and one woman. The woman was smartly dressed in a chef's uniform, a white apron jacket and a towel slung over her right shoulder. She had a trim built and perfect posture. One of the men was older, with graying blonde hair, spectacles, and small wrinkles at the corner of his eyes. The other wore silver wire rimmed glasses, jeans and a white t-shirt. A long table had been set up at the back of the room, it was covered with a white table cloth, a small cooking station sat on top: a hotplate, pots and pans, a cutting board, ingredients of

rice, black beans, chicken, and an assortment of spices. The chef stood behind the table with one hand on her hip, the other gesturing at the food and equipment.

The older male speaker started the afternoon off with a presentation . He had pinned up at the front board large posters of food charts, showing the four food groups, each one highlighted a different color. There was also a questionnaire to fill out. Whilst filling it out, Mary made a joke that children in school back home in Uganda would look over each other's shoulder and copy, "They even copy the other person's name onto their own page by mistake sometimes," she said and laughed.

The speaker covered the main features of a balanced diet, how much to have from each category. He said the organisation he works for was founded when a group of people with diabetes that had been meeting regularly to cook and eat together, decided to formalise their activities, and introduce it to others living with the same condition. It now runs a variety of classes and programs showing people with diabetes, HIV, and other long-term health conditions, how they can eat well on a budget without sacrificing taste and enjoyment.

There was a long discussion about unrefined carbohydrates. Many people had questions about the different parts making up wheat, what gets discarded, what is retained, how that gets made into things like bread and cereal. One client put up her hand and asked if it was healthier to use honey instead of sugar, because someone told her honey has less "sugar" than sugar. The speaker gave a small smile and shook his head, as if he had heard the question many times, "No, I'm afraid there is no real difference between honey and granulated sugar, they are both sweeteners and they both contain a high amount of sugar, one is not healthier than the other." He then made a few remarks about fat, especially fat used in cooking, "Now I know

African food is delicious and Africans love to use a lot of oil in their cooking, but really, you should just use about a teaspoon of oil, just enough to coat the food. That's really all you need."

Shortly after he turned to the chef who introduced herself along with the menu she was working on that afternoon. The recipes were included in our handouts. She was going to make a South American inspired salad with black turtle beans, sweet corn, and spices. There would also be rice flavored with turmeric and finely chopped red pepper, and the main dish was grilled chicken breasts with cumin, coriander, lemon and parsley. When she was finished with her presentation she invited everyone to come up and have a taste. There was a hasty rush as people got up from their seats to queue. I stayed in my seat, Mary was next to me, she too stayed seated, and said out loud to no one in particular, "Why is everyone lining up like they are in prison?"

Work prospects

A topic that was returned to repeatedly was time. This was roughly differentiated based on legal, and by default, employment or employability, status. Namely, what to do with your time if you did now have the right to work and seek employment in the country, and what to do with your time if you were in limbo because of immigration restrictions.

Nelson was there for that day's meeting and said to the group, "Go down to the Jobcentre¹⁸, just tell them you have HIV, ask to speak to the disability advice worker there, and they can point you in the right direction. You may not know how

¹⁸ The government agency responsible for assisting with employment and benefits.

much your body can work yet. You need to know your body. Your body will tell you. I was saying to Diane, this afternoon, at two o'clock, 'I am *exhausted*'. Some people find they can't work thirty five hours a week, so they work sixteen hours a week." Diane had a flip chart set up, and written across were the words "Fears and Worries." "What kinds of fears and worries do people have?" she asked. The following responses were volunteered:

- being turned away by the Home Office
- housing office benefit might be cut
- whether better off working or on benefits
- when I [will] get indefinite leave to remain, and if so, whether I will fulfill my dreams
- fear of outliving my children
- deportation
- will I live to see my grandchildren
- government may change my medication

A discussion followed and people were prompted to say a bit more about what they meant. "What do you mean by dreams?" one person asked the lady who had said she feared not knowing what would happen with her dreams. She said, "Well, you leave Africa for England – you have a dream – but you get caught up in all these processes... housing and that kind of thing," her voice trailed off. Another person said she was worried for her children and whether they could join her, she said, "By the time you get to have your child with you, you've gotten older, I've heard cases where indefinite leave isn't given till after fourteen years, and sometimes, there could be four children, and only one qualifies to come."

Diane nodded. She then said, “Two or three years ago, do you remember, we did this same exercise. Our fears have changed. Before, our responses were medicine and health centered. Now, it’s a good sign of direction, about our life, networks – our fears now have to do with economic independence, employment, means to make a living. Do you see? After the Home Office is sorted, you need to get back into employment, even with housing, they want you to get out.” She went on, “The government is keen to give indefinite leave, but you need to find your own place, they expect people to be sorted, to make themselves employable. The way forward is to prepare ourselves. Start acquiring some skills. A few years ago, we had health problems. Now HIV is a chronic illness. The government is not going to carry us anymore. The government is no longer going to play the nanny state.”

One person said about applying for work, “They want you to write down all your conditions, but then they will say you are unemployable.” Another person replied in agreement, “You can’t hide your condition.”

Diane insisted the support was there, “There are places like Citizens Advice Bureau. And the council has an obligation to house you. But you can’t expect it to happen right away, some people wait seven years.” One attendee who has been very unsettled with her flat, complained that she had been waiting for a long time, she said she is on the border between two boroughs as well. Diane nodded, “Social services could look for a reason not to serve you, and might pass you back and forth between boroughs.” There was a pause, one person said that if she was living in Peckham she would have been housed long ago, “It all has to do with which borough you are in.”

Diane went back to the subject of training. She reminded people again that they could come into the office any time in the week during its opening hours to use

the computers or telephones. She said she helped one person sometimes with their CVs but that overall, no one was really taking advantage of the resources available. “The way forward is to get into formal training. It makes a difference if you have NVQ, just look at a job at Tesco.” Someone shouted out, “They pay bad money!” Someone snorted and laughed, they sounded exasperated, he asked, “How much do you want?” Diane mentioned again her announcements from earlier about community and voluntary positions people could participate in: such as their borough’s local health involvement network – a community association that gives feedback about health and social care services in their area; or being a governor in a local school board. They could add these activities to their CVs, “This country respects so much these positions. And things like IT, knowledge of computers... getting these qualifications has nothing to do with your immigration status.”

She went on, “I know we have tried here before to run computer and IT workshops, and usually many of you sign up. But when the day comes a lot of people don’t show up. Do you know how poorly this reflects on us? We have to purchase and set up the computers, the training, organise things, and then only two people come. The funders then ask us, ‘what happened?’ They also are less willing to provide funding for these kinds of things in the future.”

Two separate incidents as the night ended

1) Emergency

The queue outside the office has been held up. The door has been opened and there are three women inside plus the team leader. One person is half lying on the floor, the upper half of her frame propped up, wedged between the corner and

legs of the chair. Her cap is on the floor next to her hand. Her hair is tousled and her eyes look blurred, she seems half asleep. The woman on the floor has two others on either side of her, one has her arm around her shoulder, and the other is holding a glass of water. Diane is standing opposite them with her pen still in her hand. She steps out of the room and approaches Nelson. “She has just had a small seizure,” she says to him, “What should we do?” Nelson is collecting his coat and backpack. His mouth tightens slightly, but all he says is, “You have to call her a cab and get her home, we can’t leave her like that.”

Regina, one of the attendees that day, says to me later on the bus, “She was *faking* it. I used to have seizures back home. I know what it is like. Your body will *tell* you that it’s about to have a seizure. It gives you *clues*. You *do* know that it’s coming. These people... she just did it so she could get a ride home.” She was also convinced that people lived far on purpose so they could get reimbursed more. I remembered Donna echoing something similar about how spoiled she felt some of the group’s clients were, “People always say it is so hard, so hard. Even though they get their housing covered and benefits to pay for their food. They say it’s not enough. What is considered enough?”

2) Etiquette

A group of five ladies came in as the talk was finishing one evening. They entered the room unannounced. Diane stood up quickly and moved to the centre of the room. She raised her voice, “Ladies and gentleman you cannot bring friends without registering formally! There are confidentiality issues here. We have to protect other peoples’ identities and respect confidentiality.” After things quieted

down I say hello to the woman who brought the new faces in with her. “Hi angel,” she says, “I am fine, I am fine.” Her mouth is held in a grimace. “What is it?” I ask. “She should not have shouted at me like that,” she says, “I only want to introduce them to this place. That it can help them.” I nodded, “I understand, I think she was just worried about the others being upset and wanted to remind people about the rules.” “She should come to me and talk to me on my own, not embarrass me like that,” she responded. The room clears out eventually and I help Diane carry some items back up to the office. The guy who did the catering comes with us as he has some empty containers that he wants to keep there since he cannot carry everything home at once. Diane calls a taxi for him.

We chat as we wait for his ride. Diane apologises for having shouted, “But people abuse resources, some only want the free food, and they tell their friends that they can come here to get a free meal and five pounds. Did you see how they came at the end, after the presentation and lesson was over?” The caterer was shaking his head as well, “Did you see how they crashed the party? And you know, one of them even came up to me and demanded stew after I served just the rice, because that was all that was left. And then she got angry and went back to her friends and complained that I wouldn’t give her any stew.” He continued, “Sometimes people at the groups would come up to the table and start asking, where is the fish? Why is there only one kind of meat? They think everything is free. They don’t realise how much it costs. Do you know how much it costs for me to prepare everything? A tenner per head. Plus my labor, plus travel costs. I’ve cooked for other HIV charities and meetings, and no one else acts like that.”

Not enough

There was a lady attending today whom I had never seen before. She had a strong built and a brown knit scarf wrapped tightly around her neck. As the meal was finishing she rose from her seat and said to the caterers, “That lady [pointing to one person] didn’t get to eat! You need to make more next time!” She was clearly frustrated about the food situation. In general, there was just never enough to go around it seemed. Earlier, in the queue, one gentleman had a one-liter box of juice in a plastic bag hanging off his wrist. I could hear the lady a few spots down the line say to another, “He’s not allowed to take an entire carton, you’re supposed to share.”

One person I had interviewed was running hurriedly past me, her dinner packed in a plastic tub tucked under her arm, “Hi, baby girl, I have to go, I’m homeless now. You give travel,” she waves her arm a little, “Give travel, we can talk again.”

I asked Diane later about the constant criticism that seemed to surface about the food. She sighed, “We spend about four hundred pounds on food. The boy we had a few months ago, you saw him, and he was very good, very professional. But the clients had complained that there was not enough variety with that boy’s food, he usually had just one meat dish and one vegetarian. The director was also complaining to me that he thought I was spending too much on catering. So we tried this other caterer. We’ve actually spent the same amount of money and there still wasn’t enough food to go around.” Diane sat back in her chair, “I don’t know what to do. I can’t win either way.” She said the group expects a lot from them because they know the staff are soft, lenient, on some things. “But we want to be professional too,” she said. For instance, with the travel reimbursement, the charity

used to ask for receipts, but people started bringing in receipts for eight, nine, even twenty pounds. She said their funder told them they should give a flat rate of five pounds. She was aware, though, that some people probably used their Freedom Pass¹⁹ to cover their travel costs .

Managing low mood

Diane had a list of physical health problems that persons with HIV are susceptible to, which included cancer, stroke, and diabetes. The biggest worry though was depression: 80% of persons affected by xyz suffer from depression. There was another slide about how everyone in the UK is now known to be at risk for depression, including children. Diane remarks, “Their lives are so stressful, so much is expected of them, many are prone to depression. Depression used to be about people suffering mental and psychological issues, bereavement... but now it’s completely common.” She looked from one side of the room to the other, “It is very normal to live lonely lives in this country.” She paused and looked around the room. She nodded slowly, and said, “Go for a walk, enjoy that, or meet your friends. Do some study. You can't be a world unto yourself.”

Diane says quietly, “I know many of you grieve the loss of your old life, but with the medication and the right support, it’s like, you get a new life.” A couple of attendees talk about how they have lost people because of HIV. “We’ve grieved a lot, we’ve grieved a lot,” says one lady whose husband died of HIV. Diane nodded, “It can be torture, being with someone that is at the end of their life, but you treasure that time, and you appreciate your life more after experiencing that grief.”

¹⁹ A travel pass allowing free, unlimited use of public transport in London, typically granted to the elderly (sixty years and older) or disabled persons.

Discussion

As can be surmised from some of the vignettes laid out, what made such social situations interesting and compelling were perhaps all the circumstances and potentialities outside of it: being away from home and family, current experiences with unemployment, and a challenging legal system. Equally, the sense of enclosure and redundancy these gatherings had, were, oddly enough, an element of their helpfulness. Diane worked in her capacity as the group's coordinator and leader, carrying out tasks that were expected of her and the meetings. She understood there was a great deal neither she nor the charity could resolve for their clients. In a discussion we had later in an interview, she stressed how the usefulness of her advice still hinged on whether clients had immigration applications outstanding, "Those things are very rare: people going out to the Jobcentre [to speak to a disability officer], because they are not entitled to that, as long as they got their immigration issue outstanding, pending, they don't have access to the Jobcentre."

I asked her about the small proportion of clients who continue to attend the meetings even though they have been granted permission to live in the UK. She responded, "I wouldn't say they're settled, no, not necessarily. And maybe not so confident that they can find a job. This is what some people have been granted leave to remain... and then, to take them to settle, first they search for housing; they have to stand on their own. At the same time, [they] have been ill prepared for the skills, so it's like they're starting all over again." It was ironic that the group's lessons and instruction were consistently oriented toward what participants could do to help themselves, and yet, knew full well that the majority of them would need time before they were able to fully employ many of the suggestions. This tension between

wanting and expecting clients to accept the group's suggestions and be active, and the context of waiting for rights and entitlements to be put into effect, seemed to consistently blur the line between moving forward and keeping a hold onto life as it was.

Clients had questions and yet also seemed well versed with the advice given in many of the presentations. "Good nutrition, good nutrition" Mary, one of their clients, said to me once when we were chatting about food and cooking. She was one of the first people I had grown acquainted with in the meeting. Mary had a way of repeating the two words twice – a small mantra, as if she had heard them many times and had made a habit of agreeing with the advice. She would be nodding her head and drawing small circles with her chin at the same time, nodding so surely her shoulders rocked forward. I asked her if she liked to cook. She paused for a second, then continued nodding, "Yes, yes, I like." She paused, then spoke again, "But I have only myself to cook for. So..." She shrugs and gives a small sigh and smile. It was also Mary who said to me that, "If there is one thing people die of in this country, it is *loneliness*."

These were one of the few direct remarks I heard about experiences and thoughts on isolation in London. The group certainly provided some company for people where they could feel comfortable talking about their problems and situations, whilst realising how different and specific they were to that person. For instance, the incident about the client who had a seizure at the end of one evening, the mixed reactions of irritation and doubt it received from the coordinator and another client. Or those clients that were annoyed with those who had their immigration papers approved and were still not in employment. The disagreements about water and food

preparation, arguing with Local Authorities about an accommodation arrangement, or what kind of work someone with chronic illness can do, illustrated how being sick was a factor that was hard to forget whilst not necessarily being the sole reason why life was hard.

Social stigma and the management of stigma was not a theme or focus of discussion in the eight months that I visited with this group. There were remarks about whether it was a good idea to disclose your condition to a potential employer or employment officer, but participants did not discuss instances of discrimination related to their HIV, compared to complaints about dealing with GPs, housing officers, solicitors, and each other. Stigma seemed to resonate more as a general kind of injury, created from a multitude of misfortunes and circumstances. In my interview with Diane, she offered a few thoughts that started with comments about stigma and the need for more public education. But interestingly enough, they quickly evolved into comments about how much interaction people have other people:

Diane: Stigma is still there, Daisy, it's everywhere, not only African groups... there are still some [that] believe – who think they can be infected by using the same spoon, things like that. They think someone who's HIV positive, they'll be a skeleton, things like that, not able to move.... I don't know what will remove the stigma. Probably... maybe... there's still a lot not too well known about the illness itself... I was reading... some of these academic studies, about the virus and attitudes... I found stigma is still there... there are still quite a lot of questions, a lot of doubts, and also, ok, it's only maybe... sometimes it's the political will. Once people get empowered and they are knowledgeable, people get on with life normally, get in relationships, have children, all those things. I think what's important is understanding – the understanding between people... understand each other, and these are things which they have to live with... take precautions, take their medication at the right time...

Daisy: So it's not just educating yourself, but how you relate to others? As you were saying the other day about how “You can't be a world into yourself”?

Diane: Yes... what we were talking about... communication... imagine where you live by yourself, and you don't have anyone to talk to, not even friends, you start to go... something will start to go wrong. But maybe they've got the Internet, they are interested in something, it's as good as doing some communication. But of course, those are like, the modern ways of living... but imagine if you didn't have any of that, no internet... it can be very disaster... but even better, if one has somebody, with them, somebody who is... somebody real. Life can be so much better.

Diane's reference to cup sharing with an HIV positive person was a popular example I heard several times in other contexts. Her comments about how people think an HIV positive body looks also reflected what one of the volunteers in another group had said to me. She had the impression the charity was attempting to challenge "old representations" of HIV, that of the angst ridden body, similar to the HIV positive artist portrayed by Ed Harris in the film, *The Hours*, based on Michael Cunningham's novel. The HIV positive body, as something tragic and emotionally and visually troubled, (the film's character is consistently shown in contorted positions, slouched over in his chair, head held low), has been a point made by scholars looking into the cultural interpretations and productions of the disease. Diane dropped the reference to "skeleton" quite quickly, she did not elaborate and I took this partly as an aspect of how prejudice, image of exclusion or object of fear, was most easily identified on a general level. Where there did seem to be a bit more thought were in her suggestions that people needed something other than themselves to think about. The aside she made about finding company with the Internet, as something increasingly typical of contemporary life, was another comment pointing to how the loneliness that might trouble Healthy Connection's clients, was not necessarily special to them. I was struck by her use of the term "disaster," as a situation where one does not have the Internet, which was the first time I had heard

her use that word. I followed on with what she said about it being a better experience if communication was with another person:

Daisy: Another human being?

Diane: Another human being. And somebody – somebody sort of who you have confided in. Like, maybe, for those who are not well, they wake up to say, no, I'm not so well today, somebody listening to you, so you feel accepted in a way, so also they will sympathise with you, and because they know the condition of that person, they even know how to help that person. Maybe they will say, oh, ok, maybe get you something to eat, or why don't you just rest, or maybe call the doctor, or maybe, why don't you take a shower and sleep... make suggestions. But you can imagine some people who are just by themselves, even when they hear about... something angered them, somebody who is not communicating will obviously feel rejected in a way.... Stigma also has to do with how people communicate. If people have communicated well, the stigma shouldn't be there, they don't perceive. That affects... even the people you know around you...

Daisy: So people who are more interactive, they don't think there's as much stigma?

Diane: Yes, I don't think so. People who are interactive, don't feel... because they've accepted, and they'll talk about it, they'll explain, and some people have come back to say, “oh, we are so shocked, when we try to explain our situation to a b c d, the ignorance which is out there, but once you explained it, people say, ‘we never knew about this...’ Just by speaking out, communicating with others, you lessen the stigma.

I was not surprised to hear Diane point out the pragmatic functions and benefits of having people around that you can speak with. Her response seemed to swing between empathising with shared emotions of isolation, and her professionalism/ the professionalism of support group therapy, which was intended to foster intimate bonds based on shared knowledge of personal conditions and circumstances. She went on to remind me of the profile of her clients:

Diane: Some people come, maybe not only for sympathy, but maybe they're lonely. The other thing, Daisy, you shouldn't forget about our group, most of them, when they came here, they left families back home, so when they came here, they got diagnosed, and then it's like that was the end, they couldn't go back, so they've left families, but they're staying here alone, like, suffering in anguish... but they cannot join their families. And as long as they have immigration issues, they have got an accommodation issue as well, where ever they are staying, it's something which they cannot call their own, maybe

they're staying in a bed and breakfast... or shared accommodation... So most likely, most of them, it's like... loneliness, loneliness... they're still isolated, they don't have so many people. And even here... the demographics of the UK, I think less than 2% come from Africa, but it looks like a lot when you get into the city. So given they've left their family, their wife, their children... when they come here, they can't get what they want, they don't have economic empowerment, they have now reduced more like beggars in a foreign country, so that's something which doesn't go well... a lot of self-esteem issues.

Sometimes the responses of the group coordinators to clients' questions or concerns came off as insensitive to me. Given the circumstances of participants, might ordinariness also appear to be something of an imposition? But I wondered if that had something to do with the demands of professionalism and of carrying out the tasks the group was set up and funded to do. These impositions occurred not because participants and facilitators were ignoring social and political challenges, but because they were part of the project of positive living, and they were obligated to focus on emphasising what is worth living and doing in life. After a brief moment, Diane added, near the end of our conversation, "I believe people need to earn a living. But if one is not able to do that, [because of] some kind of disability, they need to be given something... it's about equal opportunity, give them something to the level they are able [to do]."

I recalled one week when I overheard one lady say softly to another in the row ahead of me, "There is medication now, there is medication now." She appeared to be more factual than consoling, and there was not any visible panic in the face of the lady she was talking to: her brows were scrunched up, as if studying, and she was nodding. I was told later many of the attendees had been regulars for some months; some had even been coming for years. Many had adjusted to their HIV status at this stage and were no longer in shock. People in the meeting seemed reserved and

poised, with some tiredness and irritability stirring underneath. The shock of being sick had dampened over time, but it did not exclude its migration into another territory, its division into a series of other worries and disappointments.

In those two leaflets I mentioned at the start of this chapter there were two wildly different offerings being presented. The sessions described above explored how the encouragement to health amongst HIV positive migrants revealed the bewildering and banal aspects of managing chronic illness. Despite the long wait many people had ahead of them, be it for a council house, or travel documents, or for their children to join them in London, these brief group associations seemed to explicitly draw out the significance of quick time and abbreviated time: attending meetings, securing parcels of food and funds, then bidding goodbye, getting back on the bus and sitting up for the long ride home as many attendees lived several boroughs away.

This chapter has focused on the demonstration of stated organisational expertise and desires in a specific program and activity for persons with HIV. In highlighting the mundanities, arguments, debates and disagreements within, I have suggested that such help and care reaffirm less the biological commonalities, than social fragility. The phrase “group therapy” in the chapter’s title may appear contradictory to the above stated aims. But I hope to have illustrated how senses of separateness and being on one’s own are not easily reconciled or “made well” via a shared category of sickness, but that the space and gestures in acting as such nonetheless come with their own form of relief and reassurance..

In further chapters I investigate how the attempts to limit isolated situations, a key priority of support groups and community care, need not necessarily be

evaluated based on how or successful they are. That is, there are dimensions of individual lives worth reflecting on, for what they illustrate about the ambivalence and unease about the chances had in London.

Chapter 2

Chronicity

This chapter asks how and why I felt professional and normative definitions of chronic illness encountered during field work were limiting and difficult to reconcile in light of my informants' experiences. I also want to explore how we might push the depth and breadth of a wider idea of chronicity. How could the basic definition of chronic illness be stretched and made a lens for rethinking the consistencies and inconsistencies, ordinary and spectacular, of everyday life?

My entry into the thematic and issue of chronicity is through three ethnographic examples drawn from field work that highlighted being and living as a kind of chronic, repetitive, condition itself. My initial field work explorations into social connotations and projects for tuberculosis highlighted the significance of dealing with a disease that typically affected persons who were, in a way, chronically sick. I heard repeatedly from support workers and health care professionals that many of their TB patients led "chaotic" lives, often as a consequence of drug and/or alcohol problems, poor mental health, and homelessness. All of which made them vulnerable to having the infection, situations they, unfortunately, often returned to after completing their TB treatment.

I look at the reiterations of "the chaotic" in relation to persons susceptible to TB infection, and the thoughts and musings of a former street homeless and TB affected person, now tied to the screening initiative as a peer volunteer. I also reflect on the stories of two HIV positive women from Nigeria, one who has been in the country for two years without any identification or immigration documents; and

another with an application to the Home Office still pending after twenty years in London.

My illustrations are not dissimilar to the phenomenologies of migration sketched by Jackson (2008) in his explorations of a Sierra Leonean man's efforts to establish himself in London. Jackson's essay takes us through the subway rides and streets that made up his field work and data collection. I refer similarly here to my informants' trials, of traveling and cutting through into individual passages, journeys and networks, how intricately entwined they were with experiences of time as a series of injuries and grievances.

Chronic states: rethinking time and suffering

Chronic illness as defined by medical anthropology and public health disciplines reference the long term nature of a condition: its presence in the body over the course of one's life and the necessity for its management. Anthropologists have emphasised the people dealing first hand with chronic illness, giving mutual consideration to how identity and disease become intertwined, looking at how people struggle to compartmentalise their lives, or equally, how they might embrace that intertwining, in public speaking and activism for instance (Robins 2004). We could also ask, is chronicity necessarily a feature of the disease itself?²⁰ Of the responsibilities on those affected? Or might chronic also be symptomatic of the limitations of medicine and science, their capacities and expertise for finding out why something can only be controlled and not eliminated? The "chronic" character

²⁰ And this could be asked of any disease classified as chronic.

of HIV is made possible largely by pinning the responsibility of living with disease onto those bodies directly affected.

Sometimes I struggled during field work to clarify where the qualifier “chronic” really had significant footing. The transition of HIV away from the sentiments and statistics of fright is a theme that runs through the thesis. How people reflected, if they did, on their illness and circumstances, could reveal quite different sensibilities, beyond identifying the symptoms and stresses of their chronic condition.

A key limitation to clinical and health assurances of HIV as chronic is they fail to account for the everyday securities that facilitate such a status (Biehl 2007: 1112). One could argue HIV was not exactly a chronic condition for my informants, and still potentially fatal given the struggles of meeting everyday needs, such as secure accommodation and having sufficient, and nutritious, food to eat. These insecurities were likely not irrelevant to the squabbles and irritations broken out over small, seemingly incidental, matters at support group meetings.

Is there a separating of life as having chronic ills and the body’s chronic ills? How does this matter or not matter? What might it mean to be living as chronically ill or sick and being labeled as part of a subpopulation that is chronically unwell? A number of provocative and thoughtful arguments have been made of recent on the topic of chronicity in medical anthropology, crossing over productively with social anthropology and anthropological theory. Van Dongan and Reis (2001: 295) suggest anthropologists can contribute more patient centred interpretations of chronic illness, which capture in-depth the varieties and dimensions of agency:

[...] we see the study of chronic illness as going to the heart of contemporary social and cultural issues. In contrast with general beliefs about chronic

illness, which stress constraints and boundaries, we argue that chronic illness should be conceptualised in terms of what a sufferer can do, be, and have. We are of the opinion that the current perspective on chronic illness is strongly related to the worldwide socio-cultural ambivalence towards people with chronic illnesses. This ambivalence is determined by specific cultural norms concerning what a person should be and how he/she should behave. However, chronic illness cannot be determined simply on the basis of people's vulnerability: it must also be determined in relation to specific socio-cultural conditions—conditions that function as catalysts for "chronification." [van Dongen and Reis 2001: 295]

Vigh's review of a collection of essays exploring chronic crisis, suggests several avenues for opening up investigations of time and suffering:

Chronicity refers, Estroff says, to 'the persistence in time of limitations and suffering'; it designates 'the temporal persistence of [. . .] dysfunction' (ibid. 250, 259). Chronicity thereby prevents the aforementioned implosion of the concept as it shifts our perspective away from the notion of rupture and aberration towards a perspective on pervasive critical states. Furthermore, both the notion of chronicity and of crisis as a condition take the concept into the realm of the negative. Dealing with impersonal phenomena we may be able to see crisis as a value-free transition from one state to another, yet, when committed to the study of people - and their lives and understandings - crisis is not a word that can be separated from its negative connotations. It has a directly normative dimension as it is tied to an unwelcome departure from how things ought to be, signifying, as Lindquist says, 'stagnation, decline, and decay, the opposite of correct and desirable progress' (Lindquist 1996: 58). [Vigh 2008: 10]

He suggests taking a shift away from positioning trauma and crisis as isolated events, asking instead how they resonate and are drawn out as lived situations and histories:

I propose that we gain an insight into this key area of anthropological research by seeing crisis as context (Vigh 2006a); that is, as a terrain of action and meaning rather than an aberration. In order to gain such an insight we need to depart from our regular understanding of crisis and trauma as momentary and particularised phenomena and move toward an understanding of critical states as pervasive contexts rather than singular events. [2008:8]

Persistence of crisis is something Angela Garcia (2010) has also discussed in her research on the social and psychoanalytical experiences of heroin addiction in Mexico. She considers a discourse and logic of chronicity that has developed within Hispanic communities in the shape of an endless and inevitable suffering, a discourse and logic which, she argues, has provided a structure for their suffering at the same time that it perpetuates it. What Garcia directs our attention to is not just the long term negotiation of substance abuse, but how history and institutions were bound together with addicts' rendering of a period of, or cycle in, their lives. Though her phrasing and argument are in many ways unique to a local addiction crisis, she speaks more broadly to the theme of what time and living meant to her informants.

Indeed, this is relevant for a condition such as HIV increasingly deemed chronic rather than fatal. But in order to branch out from largely clinical explorations of how an illness is integrated into daily routine, there might be further conceptual possibilities, suggesting reworked sensibilities of time, location and place, relationships, and the nature of things like chance and luck.

Kind streets and quiet times

I remember being quite concerned during early days of field work with how contagion materialised as individual and collective objects. Not surprisingly, I was led to fringe groups and characters, projects and persons that are by nature premised on attending to persons living on social margins. This was by no means a cohesive "community." Often it felt like I was stitching together my own patchwork of mini ethnographic terrains. Ethnographic encounters sometimes happened sporadically.

Elements of this are found in a brief note I made to myself about bumping into a former TB patient who I had not seen for a couple of months:

[25.10.] I bumped into Dennis on the bus the other day. It was on the number 25 bus. I was on my way to one of the HIV groups. I went up the top deck and he was there. "What a small planet," I said to him. "How are you?" "What are you up to?" I asked. He said he just finished a shift with the TB screening team. I ask him if he's seen the other peer workers lately. He says, he hasn't seen the other peers in a while – L. has her own thing and only comes out with them when they're screening women, W. and J. have been out sick.

I ask him how today went. He says it was a big screening that afternoon, there were around 90 people, and they screened about 60 of them. The two nurses were also taking blood samples for a research project they were doing. Dennis pauses and looks out the window. I got the feeling there wasn't much more to say about the TB work that day and asked him how his sons were. ,

He said one of them, the "good" older one, rang him up the other day to tell him he's got a new job working in a supermarket; his younger sons are with their grandmother, and he's been out of touch with them for a while. He remarked how beautiful his two boys were. "They're beautiful," he said with a smile. I asked him where he was headed now. He said he was actually on his way to see T., the volunteer coordinator, about his compensation for volunteering, "You know how I get concerned about money!" He, rubs his fingers jokingly, grins and laughs. I laugh too, "I know, I know," I say, "T. told me this about you."

On the face of it, there is little that is extraordinary about this accidental meeting. When I read it again some months down the road, what I found it did illustrate, if in simple terms, was how something that once caused alarm shifts back. That is, disease and being sick were memories, and the present now was bound more to preoccupations with family, scraping together funds, and chatting with strangers.

Subtle reflections and asides were the real distinctive features I noticed about the citywide TB screening van's visits to hostels and shelters. Looking back, the urgency of statistics and infectiousness were less striking to me than the renderings

of time and place, as either offshoots or the causes of overall social and physical malaise.

I remember one visit to a large, newly built hostel in south London. I was standing outside the van with one of the radiographers. She looked out and around for a minute, “This is a huge space...” She pointed out the glassed corridors connecting the entrance to the other side of the building where individual rooms and facilities were located, “It’s a peculiar design. It looks like a community centre but there don’t seem to be many activities for people to do – you know, books, sports, outdoor activities.” She gestured at another area to the back which was being redeveloped into a set of self-contained flats, “That used to be empty land, but even with the flats there’s still space for allotments or something, but there aren’t any planned I don’t think.” She paused, “There’s also a lot more litter and bits of rubbish floating around than from six months ago when we were last here...”

Another time, the team was visiting central London. Despite setting up at a large day centre and being surrounded by people, some commented on the distance that seemed to remain between themselves and the groups they wanted to reach.

From my field notes:

Kat remarked that it was frustrating when they had a slow day and nothing really seemed to be happening. “That’s why it’s important we have the social care people with us,” she said. But this isn’t always possible. Apparently the bosses of the social care workers, T. and M., are sometimes not happy with them being out of the office. She commented as well that there are few nurses willing to go outside the hospitals, given the nature of their screening work – it is not 9-5 office-type hours.

Kat isn’t happy about the new restrictions due to funding changes, “I don’t want someone in an office putting people in boxes, the people that are least capable need to be seen, you need to “feel” it out, get a sense about people... what they’ve got, what they might need, if they need to talk.” She says again how important it is to have everyone involved: the peers, social workers and

nurses. “You need them out there chatting with people, otherwise the van just sits there, ignored. You need all hands on deck.”

Later on the bus back to the office, she makes an interesting remark about how the people they visit don’t really have a sense of time. She says they often say to them, “You interrupted me and woke me up at 10am” Patricia, another staff, scoffed, “They’re busy doing nothing.” Sometimes they go to hostels and shelters where staff are willing to help with the screening recruitment, but they’re not always reliable and some can’t be bothered. “These people [hostel and day centre clients] have chaotic lives,” Patricia repeats. I said to her it seemed slow the last time I visited. She replies, “Well, it depends where you go, and when, if you go to place that serves breakfast, people are thinking about breakfast, so it’s hard to get them interested [in screening].”

What I want to highlight for the purposes of this argument is the peculiar and ironic overlapping of reflections on how time was drawn out, wasted sometimes, for both the team and those they served. Their patients’ lives were “chaotic” and yet they appeared to be engaged with very little other than “doing nothing.”

The radiographer’s thoughts somewhat echoed my own, from a distance, as an outsider, there did not appear to be very much happening. Equally, however, I found “doing something” and “doing nothing” to be arbitrary terms that applied just as much to personnel interested in helping targeted communities, as they were seldom equipped to address the root causes of these seemingly chaotic lives.

I also found there could be more to the notion of “doing nothing” – in spite of the lack of productivity and structure health care workers insisted their clients were plagued by. I could remember that afternoon I met with Dennis after a screening shift at a drug rehab project. “Miss Fung!” he exclaimed when he saw me. Dennis popped out the business card I had given him when we first met, which was tucked behind his ID in a plastic cardholder slung around his neck. The edges of the card had browned and wrinkled a bit but it was still in good shape. The driver asked

Dennis if wanted a lift back, he said, “No, I’m going to talk with Miss Fung for a bit here.”

Looking back, my spontaneous visit with Dennis was a good example of that feeling of nothing really happening – of life resuming as it did before for him. Whether he lived now in sickness or in health seemed almost irrelevant, and it was an awkward question or topic to broach when people seemed more interested in talking about other things.

I asked him how the shift went. Dennis tucked the newspaper he had been reading under his arm, “It was fine. I knew a lot of the folks at this site – this used to be my neighborhood after all.” We made a right and turned the corner onto Mare Street. We came across Dennis’s old hostel accommodation. He wanted to go in. He pressed the buzzer and we were buzzed in. We walked up the small staircase into the main reception area. Dennis flashes a smile to the staff at the desk and asks if John is around. The staff recognise him and greet him, saying they will check to see if John can come down. While we wait, Dennis leans one elbow against the counter and surveys the room, “This is all different – this floor we’re on used to be the pool table hall. Notice the floor?” He stamps his feet. He gestures with his right arm, “These IT units [a row of computer desks along the left side of the room], that whole row used to be key worker offices.” He points to the far left, “That room at the end is where the head staff sat before, so they could see who was coming through the main door.” He looks around, nodding as he does so, acknowledging the changes made: the pictures and drawings hung on the walls, the glass cabinet standing in one corner filled with curios and more drawings, the staff space spread out towards the back, remained slightly hidden, but was still in view from the wide counter stretched

across in front. Dennis nods again, “It’s all nice now. It’s *really* nice, lots of light – cheerful.”

After the hostel visit we continued walking along Mare Street toward the Overground²¹ station. Dennis seemed to be friends with everyone we passed. He gave a nod to a guy sitting on a street bench eating a tin of sardines. “He’s having his dinner,” Dennis told me. A few blocks later Dennis was shaking hands with an old friend who said he was soon retiring from his teaching job. He told Dennis he was waiting on his pension. They both laughed and shook hands again before saying goodbye. Dennis asked me if I wanted to see where he used to sleep. I shrugged, “Sure, why not?”

We walked several more blocks to the local cemetery and graveyard. “This is where I slept.” He gestured, “You can pick any one of these tombstones, no one will disturb you, this is the safest place you could be.” He pointed a short distance to where the police station was. There were several police workers walking along the path, filing in for the night shift. He joked about smoking up in the rose garden one time and being caught by police for it. He said he responded by telling them he was sorry, but had he known they were coming he could have saved some for them. Dennis threw his head back and laughed out loud, showing his mouth of shiny, crooked teeth.

We walked around a little more and sat down on a bench. A big church stood across the lawn. Dennis pointed to the pigeons at our feet, “There’s never more than this, and never less.” He went on, “They’re smart, dirty and listening to every word we’re saying, if you don’t give them any food, they will shit right by your feet,

²¹ The city’s suburban rail network.

deliberately.” He waves at the different people passing through the park. I presume he knows them: dog walkers, fellow homeless. A few wave back but most nod and keep their head down. I ask Dennis what he thinks about these advice centres popping up for homeless people in the borough. He replies, “There should be more of them, but it's like a bandage, when you rip it off, the cut's still there. If they fixed homelessness in the first place you wouldn't need so many of them.” His eyes go back to the pigeons and he tells me about a pigeon he knew when he used to live here. “This pigeon would take her time crossing the street at Hackney Central station intersection. She would wait till the light went from red to green, then walk across, taking her time, at four in the morning. She knows the bus driver is waiting, watching her cross, and getting impatient!”

Dennis's intimacy with the neighborhood and its human (and non-human) society demonstrated an obvious familiarity and personal history with a particular time and place. The tendencies and peculiarities of its inhabitants have persisted in his memory. The point I want to highlight is the degree to which a sense of continuity with the past is as reassuring as it is something one might want to break away from. Dennis now has his own council flat in a different, neighboring borough. He often patted his breast pocket where he kept his house key, saying no one goes in there but himself. Our meeting and chat lasted probably no more than an hour and a half, it was a short walk from the screening site to the cemetery and park, but in that brief distance, I gleaned a sense of the continuity between social marginality and illness recovery. When he was a TB patient, the medication demanded that Dennis have some kind of regiment. Once he was cleared of the infection, the phone calls and friendly reminders from social workers and nurses stopped. That is, time had

moved on, Dennis was no longer ill or street homeless, but his body still apprehended the rhythm and movements of social peripheries.

“You have to think”

Nancy was one of the younger HIV support group attendees I came to know. She was in her mid thirties and came to the UK from Nigeria. She had not been in the UK as long as the others I met and spoke English more slowly, but very adequately. My interview with Nancy, interestingly, began and ended with the same subject or memory, which was the abuse she sustained under the hands of her former employer who brought her to London to work as a domestic helper.

She told me she had worked as a nanny for the family in Nigeria. They had promised to arrange and secure her travel and living in the UK. Shortly after arriving, the arrangement with the family turned abusive and violent. They refused her food and had her sleep on the kitchen floor. She came with very few possessions, wearing only a suit lent to her – the family said they would buy her more things when they got to the UK. But in the end, they denied her warm clothing, along with other basic things, such as use of the facilities – she was forbidden to use the shower in the family home and told she would have to bathe at a cheap local hotel. She said the only time she was able to eat was when another one of the housekeeping staff, an older white British woman, hid food and meals for her and gave them to her in secret.

After about a month Nancy found herself locked out of the house after coming back from her shower at the hotel. Her things had been left outside. She went to the police station where she met someone who took her to a nearby church.

Eventually she went back to the police station with the Father of the church to report the incident formally. They arranged for her to stay at a small bed and breakfast, but shortly after the manager said she had to leave and directed her to a social worker. After several more referrals, Nancy was given a spot in an upright chair in the flat of woman from another church in the area. After three months, this woman put Nancy's things outside of the flat and told her she had to leave:

[...] She said, because it's council room, she stay in a council house, if council see, whether she's telling the truth, [so] she send us out. And in her house I was sitting in the sitting room. I didn't use – it's not a room, she has a room – in the sitting room, I was sleeping in a small chair in the night, I can't go like this, in the night, cold, she will not put heating on.

So when she put my things down, nowhere to go, so in the night, I have to follow bus in the night. These buses, I'm not even going any where at that time, so I stay in the bus, when it stop, night bus, so that's where I stayed, all around London. When the day break, I was in Liverpool Street, I met one Nigerian person, I tell him my problem.

I don't know this person. Liverpool Street, so early in the morning, I never know the street, I don't know. So I see the person, I have a problem, so he help me to find [a] house, a small room, in Whitechapel. He helped me to pay the first month. So that's where I'm just staying now. It's a small room, because the man say the room – 50/week. But it's a small room, just one bed.

Nancy narrated a series of displacements that had a circularity to them. The repeating of incidents where her possessions are placed outside, riding night buses, being disoriented, and asking strangers for help.

She talked about how migraine headaches and high blood pressure had been recurring concerns for her and her GP suggested a blood test. She was diagnosed with HIV in November of 2010. When I asked if she was sick in Nigeria, she shrugs, “Maybe, I can't say.” She says she feels “safe” in the hospital, which leads to reflections about how different things were compared to Nigeria:

N: I heard [about] it [HIV] before; nobody will come near that person with HIV [in Nigeria]. People normally die. You have to pay. Some places there is no medication. People will speak. Hospital will not treat you, they will not take care of you. At that time, my hospital [in London] said, Food Chain, they brought something for me. They got it for me, for 6 weeks, 6 weeks. November, they tell me where I can meet other men, women, like, positive women, I can go.

D: Is it helpful?

N: Only Food Chain that brought me food for six weeks.

D: So it's mostly talking?

N: Just talking, every day don't give transport... only talking talking talking, then you eat, they will cook, it's the last Saturday of the month. Women and men, it's mixed. Yeah, friends, just talking.

D: What do you like about Healthy Connection?

N: Healthy Connection is good, they give transport. They are good.

D: The groups try to help people feel happy, but it seems hard for people to feel...

N: that way! [Laughs] You will feel happy that moment. Everybody gather with you – when you go your house you have to think [chuckles].

D: Once you leave the meeting, you go home...

N: ... you have to think.

D: But during the meeting, you don't have to think ...

N: You cover it [her voice is barely above a whisper].

Her last sentence struck me with its clarity and frankness. I was not sure if she meant one has to “cover” the HIV or one’s problems in general. But her remarks spotlight her experience of what she found to be the artificiality of group support. Nancy and I crisscross different subjects and themes. She highlights the practicalities and functions of charities and groups, the things they accomplish and help her with managing HIV as a chronic illness. Namely, the meals and food delivery service, and the money she can get to reimburse her travel. She also, though, talks about not having to “think” when she is at the meetings, noting succinctly one of the ironies of group therapy, where the HIV, or how it makes you feel, is something to be hidden, something you “cover.” The issue of “having to think” is woven through as a constant, like a heartbeat, a pulse that keeps beating.

Continuing life as a “sick woman”

I describe next here an instance where I accompanied one of my informants to her monthly reporting to a UKBA office in south London. Esther was one of those persons with HIV who had, very unfortunately, developed a number of other illnesses and serious health problems over the course of her twenty years living in the UK . This included diabetes, a chronic leg pain problem and high blood pressure. I took this scene with her as an example of the compulsory bureaucratic activities she was required to do, a part of her schedule, along with attending the support groups and weekly classes at a local college, (which were not compulsory). The regular reporting to the office were one of those routine practices reminding her of her uncertain legal status.

We met at the McDonalds near St. Thomas Underground²² station. I had been confused about which McDonalds since there were two and rang Esther's mobile to check, “I am at the corner of Oswin and St. Georges, in front of a busy coffee [shop].” I soon spotted her, dressed in a black turtleneck sweater and a long blue skirt; large brass flower earrings were clipped to her ears. She said, “We'll tell them you're my support worker, otherwise they won't let you know. Normally my support worker from Terrence Higgins comes and she's got her badge. But it's fine, we'll tell them you're a voluntary support worker. Because they know I'm sick, a very sick woman.”

As we started to walk she hooked her arm into mine and said again how we would tell them I was a volunteer support worker. She paused mid-step to tell me about the certificates she just received from college, “I brought them to show you.”

²² The city's transportation system, also known as the Tube.

She paused at a bench and pulled the certificates out from her bag. She had passed the first two parts of Adult Literacy, after passing Entry 3 she could move on to Level 1. I gave her my congratulations. She said she was also doing IT classes, similar to NVQ type classes that come with certificates.

When we reached the office I realise I had passed it on my way to the McDonalds. It was small, on the ground floor of a medium sized concrete building with pebble stone textured walls. Women and men were hanging around outside, hands in pockets, checking mobile phones. Esther was holding her envelope with the UKBA letter. Inside they were doing bag checks and we had to put my bags through the scanner. A black guy, friendly-ish asked if I had identification. Esther stepped in, "She's my support worker." He asked his colleagues if they could let me through. One of them turned to me and asked, "ID?" I dug through my wallet and handed my bank card. "That's not ID," he said. I volunteered a library card. He shook his head again, gave a small smile, "We'll let you through this time but next time bring ID." Esther tugged at my sleeve again, "Did you switch your phone off, Daisy?" I emptied my pockets and went through the metal detector after her. She reached out for my hand and arm as I stepped through to the other side.

The space was about the width of two letting offices or GP surgeries. Smudged windows looked out onto St. Thomas's Street. About five or six windows and a counter stretched along the back. There were two men and two women on duty. They were all white except for an Asian lady who pulled up to her seat at one of the windows as we joined the queue. There was a couple with a young child in a pram in front of us. Off to the side of every counter were leaflets from agencies

supporting voluntary return. One guy ahead was placing his index finger onto the fingerprinting device. It went red as he touched it.

Esther's turn came. The lady at the counter asked her if she was still living at her current address. She replied, "Yes." I glanced at the walls and saw TB Alert posters beside two of the partitions. The posters were crooked and dog-eared. The staff then told Esther the next day she had to sign again in four weeks time. Esther repeated the date, 18 July, to herself. On our way out she stopped to write it down on the back of an envelope. We stepped out onto the street and walked in the direction of London Bridge. Her mobile phone rang. She looked at the number and said it was her "sister", a family friend. They spoke for several minutes. After she hung up she told me the call was about her daughter, her sister was looking after her in Nigeria and was reminding her she needed insulin. Esther said she would not be receiving any money till Friday, "Then I can send fifty."

Let me take you back a little to what I learned about Esther and what was behind this routine task. She had left a violent domestic situation back in Nigeria with the help of a friend, and arrived in London in 1994. After a couple of months of sleeping on the couch of an acquaintance and working at a cleaning job, she overstayed her visa. Shortly after, the person who had been accommodating her became uneasy about her immigration status and asked her to leave. A friend eventually suggested she try to do something about her status:

E: So, a friend of mine said, since I've got a bit of money, she said, "Ok, let me check with a lawyer to help you to – get papers." I said, ok. She took me – that was in 2000 – she took me and, up to then, no no no problem with immigration, nothing, during that time. I was just staying with nothing. But 2000, I went to meet a lawyer, a friend of mine took me to a lawyer at Croydon. And the lawyer said he can help me. Help me regularise my stay, because I'd already been 10 years, then [nb: she uses 'then' as in 'at the time']. So he said, "Oh, when you are here 10 years, you can come and apply." So I

said, ok, and he charged *2000 pounds*, which I paid. I paid because I have some pay slips where I was working, he took some pay slips and everything. I said, ok. He really sent it to the Home Office because that really helped me a lot. So he sent it to the Home Office. The application and everything, and that was in 2000. He did. So 2004, me, I was working. They said, oh, the [agency] wants papers, they said if I don't bring nationality, she stop – I should stop the job.

D: And a national insurance number?

E: I have but the police have taken it. It's not a genuine. It wasn't a genuine one. That what was why/when I went to prison. This time I was working with a bank, in Oxford Circus. That was an agency, then, working for them. Yes, this was a bank, I was doing vending – I do the vending machines. They were asking for papers, so a friend of mine says, oh no, that's no problem, I have a lawyer friend that will help you to get it. So I went to a lawyer at Hackney. And said they can help me but I have to pay 500 pound. She said she's going to help me with IND, which is what I need, and, and NI. National Insurance, and the immigration – what [I need?], they call it, they can help me apply for that. I should come and get it in 3 week's time, from the Home Office. I said, ok. So I went, after 3 weeks, it was ready, and I paid him 300 before, when I went to pick it up, I paid him the 200. So I paid 500 pound. And he gave it to me, with my name, not a fake name, with my name and everything on it.

What I want to highlight at this stage is the series of ordinary gestures and movements she made and was instructed to go through. The repeated visits to offices, assurances, payments and attempts. She later met a lawyer who advised her and helped submit an application to the Home Office. Esther has since then been required to maintain weekly UKBA signings, which were a source of regular anxiety:

And you know, I'm used to signing weekly, after 2 years, I was – nearly 2 years, I didn't sign anymore. When I did I had a lawyer that time, the lawyer wrote to them, that I'm very sick, she can't come and sign every week or every month or any time. So I didn't go since then. After, I never went anymore. They didn't even ask, they didn't ask, no letter, nothing. But I was shocked about 2 months ago, I got a letter from the Home Office, saying, if you don't come to sign, we're going to put you as an absconder. I said, oh Jesus. And I don't have no more lawyer, I don't have a lawyer. I said, what can I do? So, THT, Terrence Higgins Trust, they gave me a lawyer and they gave me a support worker.

With the support worker, Esther went to an immigration advice centre to see a solicitor, who assured her that the time she has lived in the UK was nearly evidence in itself of her right to stay in the country:

She said, “Well, don't be afraid, 99.9% they *can't* remove you from this country. You have nearly 21 years already. September [Esther raps knuckles against table], it [will] be 21 years. It's because all the lawyers that you've been using they were so stupid.” She said, “Because they didn't know – they didn't do their job properly. You've been here for too long too long that somebody will say they want to pick you and take you home.”

She repeated that she was a “sick woman.” She had requested a doctor's report to give to the UKBA office she reported to, but said the doctor's office asked her to pay a fee first, which caused huge frustration. However the incident over the doctor's report fee changed swiftly into her ongoing depression, and upset about leaving her children in Africa, prompted by a telephone call from a local psychiatric nurse:

I was even crying on the street, then my phone rang, on my phone, when I look at my phone, it was my – district um, my district – my district psychiatry – this nurse – because I go to mostly, I got some psychiatric problems, of depressed – because you know, I told you, I've got 3 children back in Africa, so I can't understand that 2 of my kids died, yeah, so I only have one left now. Two of them died. So, during that time I was really mad that – that I went – I nearly went crazy. I nearly went mad. And I even take some tab – medication, I wanted to kill myself, 2006, I nearly killed myself inside the house. The ambulance has to take me to the hospital, and ask me, how many – how many of these are you taking? I said, then, I was using, umm not – Truvada now, not – the one – the one – there's one HIV tablet then I was taking, I nearly finished the whole bottle. I nearly finished everything, the blue one. I killed myself – what is the use of staying here? If two kids die, what am I doing here? There's no need to stay anymore.

Esther's consideration of simply ending her life, and cutting the threads that had been holding her up, was narrated as a natural extension of anxiety and distress accumulated over time – of going mad with grief. She asked an acquaintance at her

church, who went back to Nigeria frequently, to help her find her daughter. This person was able to locate her eventually. Now that Esther's assistance with social services is organised, she sends money to her when she can, "I speak to her regularly now. She was telling me, "Mom, I don't have no shoes – my shoes looks bad." So I bought this for 10 pound." She picks up the shopping bag next to her, pulls out the box and lifts the cover to show me the shiny white trainers inside. "She still struggling, because she didn't go to any school to very high, one thing – one thing that really – really burned my heart is that she's very sick. I never new that. She had diabetes as well. And she has sickle cell anemia. I never knew."

Esther's narrative reveals the links made between her own being unwell, and that of her children. She elucidates not only the predominance of physical and mental health frustrations, but also the continuity of distress between different institutions and individuals she has found herself amid in her attempts at reconciliation, with the state and her citizenship status, and with her children.

Returning to the scene where I accompanied her to the UKBA office, Esther and I walk back outside. We cross the street toward the bus stop on the opposite side. She says she takes the bus because she has a monthly bus pass that social services helped apply for, "If I had a passport they would've give me a Freedom Pass, but I don't have [a passport]."

People are going in and out of the Tube station behind us. A mother with a pram and an older couple with a map in their hands walk past in front of us. Esther and I continue to wait. She pulls out a small blue pillbox and shows me the tablets inside. There are about six or seven in the three compartments. She does not take insulin injections but tablets. She points out each one, "This is for diabetes, this is

for HIV, and this is for high blood pressure.” Shortly after, the number 343 bus arrived, we boarded and walked to the last row of seats at the back. She said she would take the Tube but has no money left on her Oyster. The issue of passports and Freedom Passes brings up thoughts about the pros and cons of ID. She said Nigeria is developing an electronic passport and a West African passport that would make it harder for people to do forgeries. She said she could get a new passport if she had the money. But then again, she repeated, without her passport, it was not possible to identify her country of origin:

They [the Home Office] can’t deport you unless there’s a reason, or if you’ve committed a crime. If they sent me back, officials at the border won’t know where or what to do after. I also have to sign something agreeing to deportation. So it’s better for now, to not leave. The Home Office lost my old passport but I don’t even want it back now. It’s expired, it has no purpose. If they give me my status, I will apply for a new passport, and I’ll apply for a West African passport as well.

She has a new solicitor, “An Indian lady, she said she’s not assuring any promises but she’ll do her best.” Esther pointed out the old law office she went to before as our bus passed it. Apparently the Home Office sent Esther a letter three months ago to her old mailing address, so the letter was returned to sender, “Now I’m trying to find out what was in that letter.”

Discussion

The frustration with time was a thematic that crossed over between my informants and myself, albeit in different degrees and qualities. There is the temporality of HIV, as something whose continuity and stability over time is a good thing but the success of which hinges on routine needs being met. There is also the issue of being situated within a timeline that is cyclical rather than progressive – with

a clear endpoint. There is a difference obviously between waiting for a bus, waiting to hear from children, waiting for medical test results or outcomes of a court appeal. But it is precisely the multifaceted inhabiting of time I want to stress. This chapter has argued that the “chronic” in illness demands exploration of the varying temporalities and nature of grievance, looking particularly at the sense of inhabiting “petty time” – of time somewhat wasted. Dennis had been a classic example of a someone “at risk” for TB (or any other health problem), with his history of street homelessness, and indeed, much care and attention had been given to him in the course of his TB treatment to ensure he adhered to his medication. Now that he was “better” he put in the odd hour as a volunteer but more resonant are his memories of the places his body used to be in – perhaps the very places that made him vulnerable to the infection in the first place. Nancy and Esther were struggling mutually with the implications of their illness and precarious citizenship, past events of violence and poor guidance. However, the “pastness” of these situations was weak, a thin membrane separating previous and current anxieties.

On several occasions near the end of an interview, I tried to ask some of my informants where they saw themselves in the future, in several year’s time. I say “try” because the notion turned out to be an awkward one to introduce. It was often met with a moment of silence and did not yield particularly thick responses, which is not to say that the brief answers did not point to meaningful things. One or two mentioned wanting to travel outside the UK; Esther said simply that she hoped she could bring her grown daughter to the UK, and “spend some time with my girl.” Another informant, Mary, a woman from Uganda, who I discuss further in chapter six, spoke matter-of-factly:

M: I think things will be the same. Because now, what I'm thinking as a person – at my age – now it's because, I've not been working – I'm not suppose to work. But at my age, with my pains – even if I get papers, I will not be able to go to work. Because now every part of the body is paining. I don't know whether it is age, whether it is the medication, what it is, I don't know.

Nancy's reply I found especially striking. She gave a small laugh when she heard the question, "When I was in Nigeria, I was thinking like this, and they used to laugh at me, because I was thinking like this. They will say, "You don't have money!" People will be laughing at you, "You don't have money!" [In] Nigeria, you have to suffer, you have to work for people like the woman that brought me [here]."

The swiftness, with which my question was met with comments about the present and the past, highlighted the juncture at which liberal senses of future and agency encountered its limitations. That is, for responding to more measured and calculated senses of the future, demanding more careful understanding of what a person and body does and endures, and what has been said and done to it. The material I have presented here raises questions about whether chronicity is more about inquiry into experiences of time, or simply spotlights further the presence of injury and suffering. What is interesting about the responses referenced above is the degree to which, I would say, they were spoken as a sense of self-knowledge about what the body tolerates and has tolerated in the past. I did not get the impression that informants wanted me to know how much they have suffered, but rather to understand *what has happened*, and what continues to happen.

This chapter has demonstrated how the marking of bodies as being in mode of constant crisis or distress can be considered in further dimensions, particularly in how instances of crisis are reflected on, teasing out the kind of imprints they leave,

as well as their evolving. Bringing in discussions of crisis usefully opens up the medical anthropology stream that has entertained chronicity via specific conditions clinically defined as chronic illnesses. We see the resonance of the chronic surfacing in works on homelessness, prison ethnography, and ethnographies of waiting, wherein chronicity is symptomatic of speed or pace of everyday life (Rotter 2010; Desjarlais 1997). Berlant (2007b) has looked at the notion of “slow death.” She writes, “The phrase ‘slow death’ refers to the physical wearing out of a population in a way that points to its deterioration as a defining condition of its experience and historical existence.” Slow death is distinct in that it does not operate in the situation of traumatic events:

[...] as discrete time-framed phenomena like military encounters and genocides can appear to do, but in temporally labile environments whose qualities and whose contours in time and space are often identified with the presentness of ordinariness itself, that domain of living on in which everyday activity; memory, needs, and desires; and diverse temporalities and horizons of the taken-for-granted are brought into proximity and lived through. [Berlant 2011: 100]

She takes partly from Harvey’s argument that sickness as defined by capitalist systems is the inability to work, but suggests a less pronounced distinction between being healthy/working and being sick/not working (2011: 95-96), “[...] where that experience is simultaneously at an extreme and in a zone of ordinariness, and where it is hard to distinguish modes of incoherence, distractedness, and habituation from deliberate and deliberative activity, as they are all involved in the reproduction of predictable life.”

The examples given here have highlighted how the rhythm of illness and chronicification are punctured with modes and conundrums of delay, blurring the line between purposeful actions and movements, such as ringing solicitors, getting

on a night bus, walking down an old street, and stalled movement – movement and activity that delays and distracts. I have suggested that a consideration of diseases such as HIV and TB as chronic (and not only infectious) conditions provide a platform for exploring a broader psychosocial trajectory of ills and wants, bound to ambivalent stretches of time. Without doubt many studies have thoughtfully considered issues of coping (Anderson 2013), and reworking or reinterpreting of biomedical guidelines and breakthroughs, such as social or cultural adjustments to dietary suggestions, or attitudes to taking daily medication. A question I have raised here is how and when the waning of biological urgency and trauma into a chronic state might expose another layer of vulnerability, one that is drawn out with little conclusion or outright confrontation or resolution.

In the chapter that follows I query further some of the “unsettledness” I observed amongst informants, but with an eye to the city as a stimulant for reflection and its functions and effects as an interlude.

Chapter 3

Unsettled bodies: between home and homelessness

“The city is the foremost place of our meeting with the other” - Roland Barthes (quoted in Jacobs 1996: 4).

This chapter argues the ordinary use of a city's spaces and facilities contain and guide more spectacular and taxing disappointments. I illustrate here with three examples that speak to the overlapping of disruption and continuity. One example is an anxious telephone call I received from an informant being kicked out from her accommodation. Anxieties about having a place to go and where to stay were an ongoing theme for this informant. Often she seemed sustained within thin threads of momentary respite. A second illustration draws from an extended informal encounter with a participant that took place over two social visits to local cultural and tourist sites in north and south London. The third illustration looks at a broader cluster of instances where the city presented occasion for reflecting on the past and present.

The city comes in the interactions with it, forced or desired. Whatever its nature and degree, feelings of belonging or being a stranger unfold in concrete everyday places: streets, shelters, buildings, rooms, boroughs, the Tube, buses, night buses, churches, cemeteries, hospitals, clinics, care homes, hostels, shopping centres, supermarkets, pedestrian crossing, parks, department stores, and coffee shops. Looking through my notes and notebooks, I realise in retrospect that many pages reflect a kind of meditation and exploration, both fleeting and sustained, with informants' (along with my own) more mundane, solitary and harried moments with the city as a place, with its patterns of order and chaos.

I found these encounters of moving through the city with informants particularly interesting in light of the self-care and self-help projects, which sought to create a “safe space” for persons affected by HIV. The groups touched on the role and functions of positive affect in remaking one’s lifestyle, and in establishing an immediate atmosphere of inclusion and diminishing of difference and stigmatising markers of identity. In some respects, it was probably easier for charities to define what a safe space was for them in their respective projects, than it was to define an unsafe space. Often, this did not go beyond saying the charity’s meetings were free of prejudice, ridicule and shame, and thus, founded on principles of respect and confidentiality. The terms were largely interpersonal ones of feelings, distrust and hurt. “Stigma” was the most repeated phrase in identifying the cause of harm “out there.” It was because of the stigma surrounding HIV that clients were compelled to keep silent in their suffering. Casual and formal chats in the group often demonstrated the reality of stigma that some clients faced: being turned away by partners and lovers, shelter wardens, hairdressers and others. But these challenges also seemed much more layered and complex than could be summed up by the word stigma, which maintained an air of ambiguity.

Might it be equally relevant to ask or challenge the overarching perception that “out there” is “unsafe” in ways which have little to do with HIV? Something I also try to raise here is how might the city be somewhat innocuous in its own way, affording certain moments of freedom, and points for reflecting about passings of time and how people are passing through along with it?

Interrupted place

Migration literature and research on place has been closely investigated in terms of home, homeland and belonging, homes that are made in the present, and those imagined, as a point of unity and/or conflict. It has illustrated the nature of movement to and settlement in new towns, cities, regions and countries. Anthropologists and urban geographers have made explicit points about city spaces as uniquely dynamic social economies, particularly citizenship movements, and the diversity of assertion of *rights to* the city or some aspect of it. Holston and Appadurai (1996: 200) stressed some years ago:

Nor is it to consider the city as a mere spatial metaphor of social relations [...] the city is more important to the conflicts of belonging than these options indicate [...] we might say that the city both provides a map of violence and establishes its features. In this geography of violence, the city can be pretext and context, form and substance, stage and script.

They urge for deeper consideration of how cities, “[...] spawn class fragments, ethnic enclaves, gang territories, and varied maps of work, crime, and kinship” (1996: 200). However, I make a departure from collective representations and mobilisations to look more at the transient aspects of urban place, here, defined as a living in and passing through, London, from the vantage point of bodies with relatively segmented social and emotive attachments to the city.

Home and the unhomely are two sides of the same coin as Freud (1919: 219) argued in his article on the uncanny, “The word heimlich is not unambiguous, but belongs to two sets of ideas, which without being contradictory are yet very different: on the one hand, it means that which is familiar and congenial, and on the other, that which is concealed and kept out of sight”. The familiar can grow strange in the same way that the strange can evolve into the familiar. What is interesting and

relevant for my purposes here is that the concept allows for the unpredictable impacts of time on the meanings of home and the places where it is established. Another thing I want to emphasise is the distance maintained between wanting the feeling of being at home and at the same time, not being at home in case something does not work out.

Gay Becker (1997) has written about the role of “disruptions” in redefining life cycles, arguing that as such, continuity, or the reestablishing of continuity, takes on deeper resonance:

People’s efforts to create linkages with the past during times of disruptive changes – whether societal, such as those caused by a revolution, or individual, such as the onset of illness – have been readily observed. People maintain continuity with the past amid the facts of change by interpreting current events so that they are understood as part of tradition. The ongoing interpretation of events and experiences enables people to make sense of their personal worlds; and a knowable world provides a framework for understanding major events as well as everyday experiences. A sense of continuity is captured in ordinary routines of daily life, the mundane and comforting sameness of repetitive activities, such as drinking a cup of coffee with the morning newspaper. These activities give structure and logic to people’s lives. [Becker 1997: 4]

She goes on to write:

In all societies, the course of life is structured by expectations about each phase of life, and meaning is assigned to specific life events and the roles that accompany them. When expectations about the course of life are not met, people experience inner chaos and disruption. Such disruptions represent loss of the future. Restoring order to life necessitates reworking understandings of the self and the world redefining the disruption and life itself. [Becker 1997: 4]

Becker’s remarks about disruption and continuity are worth revisiting. Her comment about social and personal expectations of one’s life course, namely, the extent of unmet expectations, have become a critical theme and point of elaboration for a number of scholars reassessing the parameters of a “good life” in contemporary

neoliberal economies (Freeman 2007; Berlant 2011). This body of work puts forward a further, psychoanalytically inflected, question of how and why certain expectations persist despite repeated disappointment and let down. Nevertheless, Becker's use of the term "expectation" over that of norms and having/being normal, perhaps spotlights a consideration of more *specific orientations towards* something. We can also add another question to that of how people experiencing disruption go about restoring order: how and when does this happen and/or fail? How are disruption and continuity constituted as a continuum?

Loony times

Regina was a close informant who consistently had frustrations with accommodation. About six months after I left London we spoke on the phone and she told me how she was, for the time being, living better with her boyfriend, now that he had been allocated a one-bedroom council flat. The last time I saw her she was staying with him in a small transitional studio, arranged for him by his old hostel. Regina was never happy with the idea of her boyfriend, who had a lot of personal and health problems, living closely amongst other people who had similar drug and alcohol problems. She did not see how that was helpful to him and was sure it would do little to encourage him to change his behavior. She would often say of the building where his studio was, "That place is a looooony house!" Before moving in with him, she managed on a number of haphazard arrangements made with friends, friends of friends, emergency shelters, and the pensioner she looked after. However, one evening in April, when the nights were still very cold, one of these arrangements broke down. She telephoned me to tell me about it, explaining

how the woman she was staying with told her she had four hours to remove her things from the flat. Regina was at a loss as she lacked the identification many places required to access services, and all the winter emergency shelters had closed for the year.

A number of upsets with her partner and charity workers were precisely over what she felt were inconsiderate responses to her situation. The hostel where her boyfriend was based at the time did not permit overnight guests, and the wardens at the pensioner residency where she spent her nights, came in at eight in the morning to start their daily shifts, she would leave usually in the early hours at five or six to avoid chances of being caught. During winter there was confusion between HIV charity support staff and winter shelter staff about her good standing in the shelter. In one incident, she had been referred to a shelter outside London that had beds for only one weekend.

The reason I go back to this crisis of her being kicked out is to give an idea of my initial window into homelessness as an emergency and also how, despite the seemingly numerous individuals she, in theory, could call on: her partner, charity personnel, her employer, friends and acquaintances met at the groups, no one could do very much. Although Regina's case may be an extreme, and she was in a more taxing position given her legal confines, she was entitled to try, with much being left to chance, luck and the decisions of others.

When there were periods of stability, Regina was quite cheerful. Most of the time, when we met, especially when the weather was fine, we spoke about other things. We would chat on the top deck of a bus, walk around interesting shops around Oxford Circus and SoHo in central London, attend church, sing, pray and

listen to the sermon. Perhaps it was precisely because they were moments “in between” the business of sorting life out that they, or the city we hung out in together, gave the impression of equivalence between Regina, myself and London, which we were both calling home for now.

Given her position as a visa over stayer one might think she was constantly in fear of being caught. She said when her boyfriend was drunk he sometimes made nasty jokes and threats about “calling immigration” on her. This threat had become a recurring theme in their relationship and she felt at this point he said it out of spite. In one of our earlier conversations I had asked her if she felt nervous about seeing police on the street. At that time she had shook her head and said no, she would just walk in the other direction or cross over to the other side. She appeared calm and confident.

As I was preparing to leave London and return to Edinburgh, Regina was settling in with James in his studio. She told me the flat had plenty of heating piped through and she could not stop saying how much she was looking forward to that year’s Christmas. I spoke with her on and off after I left London, before and after Christmas, and it turned out there were several breakdowns between her and James. At one point, her psychologist had her admitted to a mental hospital after a failed suicide attempt. She said James did not know where to find her and was worried. Apparently he apologised and even said he was the one that should have been in the mental hospital, not her.

Despite the repeated upsets and frustrations, Regina stayed with James. Her relationship was one of the main things she talked about during our first interview,

regardless of everything, she wanted to work on it because it was one of the few choices she had. She liked him and said he accepted her for who she was.

When I visited with her again during my writing-up period, she and her boyfriend had just moved all their things into his flat. I can recall how she waved to me from the window as I rang her mobile phone to tell her I was getting close to their flat. I suddenly recognised her, along with her collection of silk flowers that she had placed in the front window. She was ecstatic and showed me around the flat after we hugged and greeted each other. She took me to the kitchen first and offered me a cup of tea. It was an overcast day but a small shaft of light drifted through a little window above the sink. There were mismatched dishes across the counter and half opened packages and boxes of food. I commented on the fresh basil pot she had in one corner. "It's my first plant!" she said, and laughed as she took out cups and tea bags and put the kettle on.

She handed me my tea in a cup with the face of Sponge Bob on it. We went into the lounge, which had mismatched chairs, and two large television screens set up. I could see her flowers in front of the partially curtained window. We spoke about the things we had grown used to discussing: her health, how things were with James. She seemed changed: her face was a little fuller and more tired, she was much more anxious than when I had last seen her. The topic of fear of Home Office officials came up again, despite that she was now in a slightly more secure living arrangement. She said she had been watching the news more and heard about the raids being conducted around the city to catch illegal immigrants. She said the police have been going to major Underground stations because they know there is only one exit and that they can confront people more easily. Her voice quickened

and she began to cry, “This is why I don’t like to take trains, because you have nowhere to run. At least with the buses I can get off and go in the other direction.” She did not sound as casual about as she did when I first spoke to her.

I asked if she has had any visitors or friends over to the new flat. She shook her head, “No no no, I don’t want people from the groups knowing my business, people would be jealous and start gossiping and telling stories about you.” After her boyfriend had gotten up and was out of bed she showed me their bedroom. The bed was made up with a lavender coloured bed cover; an oak wardrobe stood against on wall, a dresser on the other, a window looking over an unkempt garden was at the opposite end. She pointed to the nightstand on her side of the bed, on it were two books, a dish of holy water and a little Virgin Mary figure, “This is my holy table, I really like this room because it is *calming*. I can sleep and rest, read my bible, do my prayers.” She jokes that James has been complaining that she is not making use of the two televisions he bought for the lounge since she spends all her time hanging out in the bedroom. “This is my favorite room in the house,” she said.

Local excursions

This second illustration involves another informant, Tabitha. Tabitha’s situation was similar to Regina’s in that she did not qualify for any welfare support from the government. However, it was also quite different as she had an application for permission to stay submitted to the Home Office that was pending a decision. She had a grown son working and studying in Luton. Tabitha was renting a room on her own in a shared house. She had worked as a carer in London before finding out she was sick. She said her health was much better than it was before and she had

adjusted to her HIV. Her main worry now was her application, but she also knew she had to occupy her time some how and would attend group meetings when she could, she did voluntary work handing out leaflets for another charity once a week, and she said she was trying to get back into reading again and visited the local library more.

The conversations and exchanges that took shape around our walks and excursions had a different quality and sense about them compared to our taped interview. Some of the things we saw seemed to remind Tabitha about her family and relationships with her siblings. I wondered if in walking around London we were going through the motions and channels of being normal, being like everybody else, like any other visitor in London, whilst being consumed by events and memories?

In his article reflecting on a walk taken twenty years earlier in the same neighbourhood in New York with a former informant, Irving (2010) discusses how central walking was to opening windows into his informant's memories and sensibilities, "By walking around familiar spaces while narrating the objects, places and people they encounter, my co-walkers offer glimpses into the streams of thought, mood and emotion that comprise their lived experience but exist beneath the surface of their everyday public activity" (Irving 2010: 25-26). Indeed, it was a wholly different experience speaking with Tabitha as we literally put our bodies in motion, in proximity to the city's streets, sites and sounds.

Had we walked individually on our own, the sense of individual personhood dissolving within a complex urban grid, which Simmel (1903: 23) alludes to, might have been more pronounced. But in joining our mutual isolation, the city's

environment became more stimulating rather than alienating. The places we visited were not familiar to us in the sense that we had seen them many times before. Both of us lived in different parts of London and usually did not stray far from our local areas. I ask as well here in this chapter if our encounters speak to the senses of hospitality of the city, less as something expressed through people being friendly, than as a feeling emerging through diverse dimensions of a city's geography, cultural and aesthetic variety, and the sharing of anonymity within a crowd?

It was not always easy for Tabitha and I to connect. We usually blamed the weather. This frustration of being close and yet very far is captured in some of my rough notes from the time:

On Saturday I met with Tabitha. We'd been exchanging emails and texts back and forth the past two weeks about having another outing. One afternoon I was free but she wasn't (she had trips with the other support groups, meetings etc.). Other days it was rain and showers that stood in between. I could picture each of us with the phone to our ear as we peered out the window, seeing the grey clouds looming above, our brows wrinkling. I remember thinking her suggestion that there'd be time to meet closer to the end of this month – thinking that was far.

But the visit came the other day. There were clouds but blue skies too. I texted her at around quarter to 10 to meet at Embankment station at 12:30 for a walk and chat along the Thames, plus a visit to an exhibit at the National Theatre in Southbank. She said she'd be there. When I came out of the station there were claps of thunder and a splatter that turned into downpour. I huddled in front of Strand News in the station and texted her my arrival and where I was standing. It was getting crowded so I moved closer to the telephone boxes, by the wall with the station and area maps. I watched people swipe out, the expressions on their faces when they saw the rain: Oh no, and you said you didn't need your coat; I don't have an umbrella; oh my God, look at that.

Eventually I saw Tabitha come through the barrier and waved to get her attention. I told her about the exhibit and said it is just a short walk from here. She nodded and said that was fine. She said to me, "You know I was lying in bed when

you called, then I got your text, and was going to say if we could make it for 12:45, but then I said, no, I can make it for 12:30. So I jumped out, dressed very quickly, I thought you might bring your camera so I wore this shirt [it had red in it]. Sometimes with this immigration thing, there's no motivation. But it's better to be out, rather than staying at home and imagining what I could have been." She looked around and remarked, "There are lots of people around aren't there? I guess they're just enjoying the area."

On our way up to the photography exhibit we stopped to look at a small selection of textiles and prints set up on one of the lower floors. I asked her if she had decorated her room at all. To my surprise, the question prompted a longer discussion about her siblings and family. She said she had put up a few pictures so the space was not so boring, but the real artist in her family was her elder brother who died a number of years ago. He had been a famous musician in Malawi, "You know, whenever I hear about a CD Stephen did that sold for millions, I just think, what if he'd been alive today?"

Tabitha was close to her brother because he looked after her when their mother died of a hospital infection, "My elder brother would take me to the hospital if I were sick. He did what would normally have been something your mother would do." I made a remark about time not always being the greatest healer. Tabitha nodded, "No amount of time can change how you feel about some things, people you've lost."

We paused to look at a couple of photos. There were quite a few featuring the politicians Nick Clegg, David Cameron, and Gordon Brown. Tabitha commented that Brown did not have a connection with people, "There's something

over his face, he's nothing like Tony, the confidence and presentation of both Tony and Cherie... Brown was a great chancellor but not a great PM, he didn't even get his position via election." We came across a photo of Samantha Cameron; Tabitha crossed her arms, "She is no Michelle Obama. She is quiet, and let's her husband do the talking." There was a photo about the story where Brown was caught saying to someone that the lady he had spoken to was a bigot. Tabitha turned to me, "Don't you remember that story? Well, I've been here for twelve years, you learn something about the politicians."

We browsed a few more pictures. One is of a high-rise in Glasgow famous now for asylum seeker suicides committed on its premises; there is a photo of a Kurdish man who is now married to UK citizen but still has no status of his own. Another image of a mother and baby in Sierra Leone based on a story about the country's devastating infant mortality rate. Near the end we come across a rather cryptic picture showing doll pieces being assembled, it turns out the dolls are made for grieving mothers – they are replicas of babies and children lost to stillbirths and miscarriages.

Back outside we continued chatting and walking. I noticed Tabitha put a lot of thought into our conversation. She would become very enthusiastic at some moments and stop mid-step, keeping still while she gave me an explanation or answer to a question I had asked. She had mentioned on the phone two weeks ago about visiting her Member of Parliament (MP), and trying to get an appointment with her MP. Tabitha said, "Well, I couldn't meet the MP but I met his staff, which is like the same thing since they do the work for the MP anyways. My solicitor also sent the Home Office a reminder, saying we are losing time." She said she received a letter

from the Home Office that Thursday saying they would have a response within the next six weeks.

I asked her a little more about her family, if they knew about her health and immigration problems. Tabitha thinks her sister died of HIV since she had the symptoms, “She never said though, but I suspect she did.” Tabitha herself has not told anyone about her HIV. She has a sister in Manchester who is a published author but she said she has never asked anything or said anything about her health. She comments that she really enjoyed the photos and the art we saw. After a while we come back to the topic of her brother, “Losing my brother, to lose someone like that... you know one year I was visiting him and his wife, and he offered to either take me out to dinner or buy me some groceries, I went for the groceries. The day I heard he died, there was still the food (bulk sacks) left – bags of sugar and flour. That was the kind of person he was.”

We passed a Jehovah Witness and politely declined his leaflet. Tabitha continued and said her niece, her brother’s daughter, had been semi-adopted by a family in France who were also artists and close friends with her brother. She was a musician as well. Tabitha shook her head and told me she would show me the newspaper and magazine cuttings she had collected over the years, “My brother broke through all those barriers of racism in the music world. It was in him. He had his first concert at 17. All the press knew him. You know, he made a list of influential Africans.” She sighed, shook her head again, looked out over the river, “Lots of awards and centres in Africa have been named in his honor.”

Tabitha shared close memories and thoughts about some of the people she had lost along the way. She and I had passed some unsettling images of tragic events

and phenomena unfolding across the world. I do not know for certain if they had an influence on the direction of our conversation. But I think our movement through the exhibit enabled a gentle momentum to take shape, and guided and contained the unpredictability of dialogue, which had taken us to the sensitive terrains of grief and loss.

About a month earlier in the beginning of July, Tabitha and I had met to visit Alexandra Palace in north London. It was more of an entertainment venue but I had read of its beautiful views of the city. After getting off my train from Kings Cross I exited on the left of the station platform I was dropped off at. I rang Tabitha and she said she was waiting at the bus stop on the opposite road, on the side of the rails going towards London. I walked up the small hill and went around the leafy bend when I finally saw her sitting on the slim bench in the bus shelter. I waved and apologised for the confusion. She laughed and said it was no problem. We cut across to the main road that would take us up to the site.

On our way up to Alexandra Palace I told Tabitha about which train I had taken and we started talking about Kings Cross station. We both nodded at each other's description about what a zoo it was, how crazy it was with all its hurried travelers. She said a homeless man had approached her one time there. He wanted to borrow some money, said he would pay her back and offered his details. She shook her head as she recounted the story, "I was, like, you are approaching the wrong person." We agreed the situation of homeless people was a very serious problem in the city. She said she had heard of terrible stories where street homeless are found dead, and just get dropped off at the morgue, with no reporting, no written record. We both shuddered at the thought.

The road became steeper as we continued. I asked Tabitha if she wanted to take the W3 bus but she said it was a short hike, “This is an outing so going by foot is part of an outing!” As we got higher up, a sweeping view of northeast London emerged. We stopped for a moment to look. She asked, “Is Vancouver as big as this?” I said there was as much space if not more, but the city was a bit more spread out. She said again, “All this time, I’ve been living here for 8 years and always passed by this place, but never came up. Imagine.”

We were approaching the top of the hill and the “palace” was becoming clearer: its coloring and building details were faded up close, the tan stone looked worn and brittle; some spots were marked with graffiti. We were not really sure where the main entrance was or where exactly we would find the main outdoor attraction. I thought we could get a map or leaflet at the desk but the guy behind the counter just gestured at a faded map pinned up to a board near the door. It did not say much other than marking off where the main exits and parking were located.

We made our way back out and decided to stroll around the property. Tabitha remarked, “From far away it looks nice but you get close and you see it could use some cleaning.” We continued walking around, making our way to the back of the palace. I was relieved to find it was much livelier than the palace itself. There were plenty of families and children using the playground, there was a small pond area with large swan-shaped paddleboats, and a small café serving refreshments – people were lounging, drinking iced coffees and juggling squirming babies and children. We kept walking, past the water to see what was around the corner. I saw another map ahead and decided to have a look. Down this path there was a row of brick houses with small gardens in front, they reminded me of a street you might find

in Vancouver, around Oak and Cambie Streets at fifteenth avenue. I gestured toward them and said, "It must be nice to live in one of those houses across from this part of the park." Tabitha said, "Yes, I was just thinking the same thing, those houses look very nice." The map was the same faded one as the other two we had seen on our way up. We headed back toward the park and pond area and decided to sit down on the benches for a bit.

She told me a little about the other community group she attended that focused on single mothers and children with HIV. They recently had a session on immigration advice. She said the speaker told them there was a push in the government to resolve the backlog of cases from 2005 to 2011. I found our talks about immigration almost always led to a series of "what ifs," but also reflections on how things have supposedly turned out for other people. Tabitha said she knew of one person who was recently granted legal status. She had asked her if she was planning to look for work now that she was eligible to do so. Apparently she was not. Tabitha said she was often annoyed when she heard this kind of thing since she was disappointed by her own situation of not being able to work.

I asked if she has recently visited the support worker who helps her with food vouchers. She has and said the voucher made a big difference. Her HIV consultant's staff also helped her acquire a Freedom Pass. "I don't know what I would do without that," she said. She pointed to the ducks bobbing across the lake, "I'm just managing, just able to stay afloat like that duck on the water."

We went back to some of the things she has heard in immigration sessions about HIV not qualifying as a disability. She said, "It used to be that if you had it, they would grant you status to remain, but not any more now that medication is

available.” I said, “But there are still a lot of risks associated with the condition, aren't there?” She nodded, “Definitely. One day you can wake up and feel fine. Next day, you don't know, you might have memory problems – something else might go wrong.”

She continued, “The medication helps you to a certain level, but it doesn't bring you back to what you were before. I know it has affected my IQ, my brain. When you are that sick, it damages you, that damage is done even after if you do start medication. People say to me what an intelligent person I am now, and yes, I can have normal conversations with people, but if you had met me before my condition...” Her voice trails off. She tells me how she knew about the sickness back in Malawi, how it was around the news, in leaflets, how she “had the information.” She gives me a rueful smile, “Now that I think about it, it was stupid to get infected. It was a small thing to ask for a test before sleeping with someone I didn't know.” She shook her head, “No, it's not complicated or difficult, and you can save yourself a lifetime of agony.”

Tabitha declined to go to the café for water or to fill her bottle with tap water in the public restrooms. I went to the café and bought a bottle of water. I offered to pour some into the bottle she brought along and she nodded and said thanks. I brought out two apples I had in my bag and passed her one. She bit into it and remarked how nice and sweet it was.

She did not continue on with her comments about HIV and we started talking about other things. Travel was a favourite subject that she often spoke about with a glimmer in her eye. She told me how her nephew was recently sent to Tanzania for business and was surprised with a ticket to Kenya from her brother and his wife. So

they all went and met up with her friends in Kenya. Tabitha reminded me how important it was to keep in touch with people who make time for you, “people who you can call your friends,” she liked to say.

We got up to toss our apple cores in the bin and use the toilets. I passed a little boy wearing a red t-shirt that said, “My favorite class is lunch.” After we came out I suggested we take a few pictures and pulled out my camera. We asked an Indian man sitting on a bench with his wife if he would not mind taking our photo. We also took a few fun close up shots ourselves. As we walked toward the exit, I said to her, “I find I need to take pictures and write things down or else I forget.” She replied that it was usually the other way around for her, with, “idle time,” she had time to “flashback.” “Probably it’s because you are busy that you don’t remember things,” she says to me.

As we made our way to the road we had come up, I asked her if she had visited other spaces around London similar to this one. She beamed as she recounted to me a trip she made to Hyde Park to celebrate Nelson Mandela's birthday. The celebration included Will Smith and his wife, along with other famous musicians, and Mandela eventually came out onto stage, shaking a bit and leaning on his stick. “Was this celebration open to the public?” I asked. “You know,” she said, “There was a raffle at one of the groups and I entered and won! Tickets were around 65 pounds but we scored a pair from the raffle.” We started walking downhill this time, which was much easier. She commented again that she could not believe she had been living in this part of London for so many years and never noticed the park and its palace. She walked me down to the Kings Cross bound train and it was just pulling in as we arrived so we hugged quickly and said goodbye.

Wirth (1938) has written about the character and flavor of urban relationships and interactions, and the implications of living in socially and institutionally dense and diverse urban settings. I have mentioned a number of times the irony of so called HIV and community solidarity groups that actually are in fact quite divided. Friendship and solidarity were most robust in the moment within the confines of the meetings. In being conscious about these afternoons out with Tabitha, of being in a social setting, embedded in the city, not hurrying, I perhaps attempted to resist Wirth's schizoid urbanism (1938: 12). Equally, I think the banal facets of the urban are just as worthy of exploration as the socially and politically charged dimensions.

Tabitha remarked a number of times not so much how the landscapes and sites we visited startled her, but her astonishment with herself in having been so close and yet so far. Our conversation and deliberations also revealed the numerous dimensions through which representations of an HIV positive body suffering in London could be shattered. It is not difficult to feel the structural features of informants' situations are the most pressing and deserving of attention. However, to hone in on identifying the main "problems" individuals faced (housing, for instance), risks, I think, a slightly reductionist stance. Something I have tried to show with the ethnography above is how layered the experience of being "unsettled" might be, of time gone astray, and I have experimented with the theme of walking as a means of giving time, and dialogue, an order.

Small passages of time

Le Marcis and Inggs (2004) have written about how persons living with HIV journey and search for care in Johannesburg, coping and engaging to the best of their

ability with the city's institutional neglect and refusal, their efforts interlaced with instances and relations of compassion and activism. Interestingly they describe their informants as neither immobile nor apathetic, or as passionate publicists of the HIV cause, but rather as individuals making a series of decisions and negotiating with the resources at hand, wherein one thing leads to another. Support groups, as they note, can be privileged sites linking to opportunities to participate in clinical trials or acquire training in community HIV activities. As they discuss in the case of one informant, an HIV positive woman recently split up from her boyfriend, her first time setting foot in an official building is via a voluntary training course at a local health department; and she continues her participation through the local HIV campaign offices in the city that sponsors the travel and movement of their staff throughout the region, visiting conferences, government offices, and universities (Le Marcis and Inggs 2004: 473).

Parts of the chapters thus far have similarly alluded to the productive dimensions of illness to the extent that time and resources are mobilised on its behalf, and sites of care and intervention are built up around it. But in contrast to Le Marcis, I have not so much emphasised the element of a quest for care across the city, though it is suggested in my discussions of group therapy attendance, and in some of the details noted about individual life histories and present trials. However, similar to Le Marcis, I found support communities were not always supportive.

There were quite a few times when I felt I had not learned much that was new at the groups, but was grateful for the moments where small talk and further appointments and engagements could be chanced. Thinking about what happens between destinations, even the smallest and most ordinary of destinations, takes me

into pockets of time seemingly lost and unmarked. I joined two women, Maureen and Ruth, from the group on their bus journey home one afternoon. We took the number 23, the number 10, and then the Underground train at Oxford Circus. Maureen knew all the routes and walked several paces ahead of Ruth and I, waving her arm now and again to gesture at which stop we were approaching. They both had use of a Freedom Pass, and they both preferred to take buses. Maureen said, "It's too hot, the Underground." Ruth laughed that she had little patience, if she has to wait more than ten minutes she starts walking to the next stop, "... and usually the bus is going past you just as you start walking!" Maureen shook her head, "I am not in a rush." Ruth held up her left wrist, "I am always checking my watch, I am always in a rush. Many hospital appointments," she added with a smile.

After she said she had use of a Freedom Pass, I asked if she had any other support from the council. She nodded and said she was on a benefit, and here Maureen nodded as well. Ruth said, "People back home, they think if you've been in Britain for ten years surely you must be rich. They ask for money sometimes. If I don't give, they think I am being stingy. They don't know that you aren't able to work. I don't tell my children, it would hurt their hearts if they knew how I was living here. I don't say anything about difficulty."

Maureen looked out the window as our bus navigated its way through closely packed streets, all of which seemed to be undergoing some matter of construction. It was held up at one crossing and we looked out at the clouds of dust enveloping the workmen. The hammers and drills pounded and agitated the roads and pavements, their quarrel drifting recklessly through our open windows. Maureen's gaze held firm and she nodded her chin as if a model or draft of a building plan had been

presented for her approval, “This is London, this is London, always construction, alllllways construction.”

Ruth gave a small laugh and shook her head, “Yes, there are no roads in Africa.” She turned to look out the other window as we passed a row of clothing and furniture boutiques, “I love looking at the shops, it gives me a happy feeling – it helps for passing time!” And she gave a small burst of laughter, adding, “Shopping is a sickness in this country.” She paused and said, to no one in particular, “Oh, I almost forgot to take my medication.” Her hand reached into her purse, she tucked the tablets into her palm, dropped them in her mouth and took a sip of water from a small bottle she had been holding in her left hand. She kept smiling and chatting, “English people are so clever to think of support groups...” Our bus passed a large park. Ruth peers out to look, “... and they have thought of parks too!” I asked her if she felt like she needed more space in London, living space or when she is out, if she finds it crowded. She shook her head, “No, you get used to it. You get used to the borough you’re living in. When I first came here I avoided the parks. And then I saw all the people there, enjoying. Later, I would go, by myself.”

Ruth had briefly mentioned during our interview that she was a nurse back in Uganda but did not elaborate. She seemed to have more to say now and mentioned being surprised when she first came to London and saw a hospital that looked exactly like the missionary hospital she had worked in, “It had the *same* cartons [for supplies] as well! The doctors at our hospital were given by the Church of England. The beds and mattresses I saw in London looked almost the *same* as the ones donated to our hospital.”

Maureen, who had been sitting quietly, her hands folded in her lap, turned away from the window to look at us, “Britain prefers to give things rather than money.”

Ruth shrugged and continued with her description, “Nursing is completely different in Uganda. You have a nurse running the entire ward; a nurse can even make a prescription if there is another nurse watching. You call the doctor only in an emergency. Sometimes there is only one wheelchair for the entire ward. You have to lift the patients, clean and sanitise... *everything*, you have to do it all.” Maureen made a joke about hospital nurses in Britain pretending to work, spending their time taking tea and acting busy.

The bus approached our stop and we got off. Maureen waved as she was heading from this point in a different direction, and her next bus had pulled up ahead. Ruth and I had some time and walked for a few minutes in John Lewis²³. The store was not very busy but there were still a fair number of people, mostly women, walking around the floor, absorbed in holding up jumpers and dresses, and setting them down again. Ruth flipped around the tag swinging from one item to look at the price, “300 pounds. With that I could put my kids in school for three months.”

After that day, I did not see Ruth again at any of the meetings for the next three or four months. I reached her by telephone eventually and we made an appointment to meet for an hour before her doctor’s appointment. I stood by the bike rack out front and scanned the Underground station entrance. I finally spotted her and saw I had missed her the first time around as her appearance was much changed. I asked her if she had managed to drop off her paperwork at the agency she

²³ A major British department store.

mentioned on the phone. She giggled, a sheepish look crossed her face, “No, I didn’t get out of bed early enough, I like my sleep. I will go later, after my meeting at 3 with the employment services people.”

Ruth tells me she has been doing well enough. One of the women from the group had recently invited her and some other people for a big meal to celebrate the end of Ramadan. She enjoyed herself. She has been concentrating on finding some work. She is considering training to be a physician’s assistant and has been going to the local library to research job possibilities. She has also been thinking about taking one of the standard English language certificate exams, but so far has only been able to do the free exercises and tests available online, since she cannot afford to take the course or buy the recommended manuals and study guides.

We came to the end of the busy street we had been walking along and arrived at the entrance to a small park. It was cool but we found a spot on a bench on the sunny side of the park’s pathway. Ruth and I took up one half of the bench’s length; a pair of abandoned crutches rested on the other half beside us. It was at this point that we got into a long discussion about how worried she has been about enlarged lymph nodes around her neck and throat. She said her doctor gave her pills to minimise the headaches and tiredness, but she does not like to have to keep taking them. Her hands reach up to feel around her neck as she speaks, her finger tips gently pressing down. She repeated that the doctor says he does not know exactly what it is or why it is happening. She rests her right hand on the back of her neck, and says, “It is really worrying. One lady from one of the groups said he husband had the same thing, these lumps, and he died six months after!” Ruth shook her head and chuckled when she saw my disbelieving face, “No no, she did not say it to be

unkind, this lady's point was that her husband had HIV but this was a long time ago, when only the old medication was available. So there is a big difference." She moved her hand to cup the space under her jaw, "I think it might be TB, from the TB I had before. But I don't know." She sighed and smiled at the same time, "It is really so stressful."

More people drifted into the park, perhaps attempting to catch the last of the sunshine before it was swept away. There were women with infants hanging in pouches in front of their bellies, another pushed a pram snug with twins dressed in pink, one man broke the pace as he pushed his stroller and then made a few quick circles while he chased a pigeon with it. A little boy's squeal spiraled into the air. Two young guys sat on a nearby bench opposite us and settled into their lunches, the warming smells of pita and kebab drifted toward us as the breeze picked up. The cool wind was gathering and sweeping. Ruth and I had both been looking down. I could see the lawn around us slowly becoming carpeted with curling, papery, brown leaves.

Discussion

Sometimes the city appeared to afford a certain amount of predictability and stability. My informants were to an extent "free" even if they did live in fear about some unknown. All reflected on some dimension of the unhomely and, interestingly, their kinship relations – be it with a partner, a sibling, friends or children. In Regina's case, she was dependent on her boyfriend for a sense of place, whilst remaining anxious about running into UKBA staff conducting raids at Underground stations – but she also felt assured that there was a bus she could board going the

other way. Tabitha did not often visit or participate in the city's sites and events, and when we did so together, they sparked thoughts about family and past and future travels, thoughts about elsewhere. The walk with Ruth in the direction of the park was very slow as she was tired that day, but she was full of calm and pleasant chatter. However, when we sat down on the bench, she seemed unable to stop her hands from reaching up and feeling the lumps around her neck. When I asked her if she has been able to keep in contact with her children she says she wonders if her children would still recall her face if they saw her now – a multitude of difficult situations to resolve, articulated on a quiet park bench. I think back to that bench now, the measure of security it offered us in those fifteen minutes, and wonder how our conversation might have been different if we had not sat down.

Irving (2005) has reflected on how walking with informants impacted his understandings of HIV and of their positions. He discusses how the very act of walking a hundred yards with his informant, Francis, was radically different from listening to him speak with ease from a chair in his living room (Irving 2005: 323-325). My supporting ethnography has shown similarly that physical movement between, and dwelling within, sites and localities bring to the surface varied injuries and alleviations. In contrast to Irving though, my emphasis has been on a sense of unsettledness, implicating the body's negotiation with pressures and limitations that postpone the reaching of the good life, or perhaps, put differently, of reaching home.

The “unhomely” persisted for informants in varied ways and forms. Participants knew how to navigate London's streets and transportation grids, some decorated and personalised small spaces within their homes, and others found popular department store window displays comfortingly recognisable. But

interspersed with these repeated actions were distance and small voids, filled with doubts and lingering apprehensions about personal security, familial ties and the future.

One of the most striking tensions I felt whilst on field work was how informants were sustained and held to the city, how it was at once in the foreground and background to individual lives and livelihoods. That is, informants were managing their illnesses because of where they were located in broad geographic terms, but they also remained slightly estranged to their immediate localities. I noticed amongst many of my informants the way health was easily sectioned off as a matter dealt with in hospital and clinical settings. And yet, a sense of anxiousness and being unsettled appeared a constant thread. The inconveniences of one's body and its interactions with everyday places and things were less easily contained in day-to-day living. This chapter considered a spectrum of sensibilities straddling between home and homelessness: encompassing the forging and protecting of feelings of comfort, novelty of exploration, and familiarity and unease with living alone.

Chapter 4

Objects of emotion: making therapeutic feelings

The previous chapter looked at some of the ironies of experiences of migrancy in London, the interplay between the familiar and the strange as precisely that which enables a sense of place to emerge, but not necessarily a reassuring one. The crafting of a sense of refuge and comfort was in some ways more compelling for my informants given their precarious social and legal situations. Here, I consider further the juxtaposition many of my informants' faced in regards to what they felt and what they were often encouraged to feel.

The support group ethnography presented thus far has looked at how the habitual or prosaic illuminated the parceling of HIV into a series of small things. It was also an effort to illustrate how group identity around illness was split and fragmented. As seen in light of some of the observations made in the chapter on chronicity, I argued a consideration of seemingly trivial pursuits did not so much paper over larger, deeper problems in peoples' lives than show how they were intermeshed. I have also attempted to explore the comfort and assurance there was in a kind of care that was by definition limited in in what it could actually do, but rich in its capacity to offer a space with few obligatory pressures.

In this chapter I take up how the chronicity of illness is communicated in terms that emphasise its emotional consequences, and the merging of these emotions into a wider bracket of self-esteem and well-being not exclusive to HIV. I look at Lifting Life, another charity where I volunteered and did a large part of my participant-observation research. In particular, I examine how feelings and emotions are a significant realm where one learns to reconcile with chronic illness and living

“positively.” The chapter argues that individual and collective dynamics about “feeling good” are central to the remaking of an infectious and chronic illness such as HIV, as manageable. The cultivating of feelings of wellness was elaborated as something that would assist with real life day-to-day situations. At the same time, the charity also cast its space as an environment where persons with HIV could feel welcomed and cared for. As such, the chapter also reflects on the fleeting nature of refuge and hopefulness provided by empathetic communal space. It explores how the making of space and boundaries constructed to be optimistic and free of stigma function to provide momentary relief from the daily frustrations, without resisting or challenging the pressures of what it means to have a normal life.

For the purposes of this discussion my use of the terms feelings and emotions is somewhat in keeping with how they were defined in these situations, as physical or outward manifestations of individual psychological states. This is obviously a limited definition but the main thing I want to get across is the kind of “staging” that can happen with individual and collective emotions. It is indeed an artificial divide to position emotions as part of the body and thinking as part of the mind. In showing how such divisions were enacted, I am not arguing that they are two separate realms, but rather aim to demonstrate how such a division is at times made meaningful.

The illustrating ethnography is laid out here in three ways: 1) in an ethnographic recapping of three session topics that captured the predominant sentiments of the charity: love and relationships, the management of difficult emotions and relaxation therapy; 2) in snapshots of scenes and encounters I experienced and took note of at various points within the centre; and 3) in clips and conversations I had with volunteer staff and visitors. In building something of a

mosaic of observations and impressions gleaned from this site, I attempt to give an interpretation that communicates an atmosphere and environment at once sincere and contrived in its inflections of empathy and conviviality.

I recall one visitor nodding and repeating, “Love yourself!” in response to my question about what she learned from these meetings. What possible shifts might there be, semantic or otherwise, from self-care to self-love? I suggest the value placed on being mindful of, and loving to, one’s self, more than just one’s condition, is central in creating both a reconciliation with chronic illness as a part of one’s life, and a distance with its power to take over. I want to stress here “mindfulness” that engages with feelings and the senses, over terms of “control” and “discipline”, which do not have any less to do with those things, but suggest an underlying regulatory function and end. I would like instead to focus more on the building of optimism within and about one’s self, how “empowerment” and self-potential are convincing through emotive social activity, namely the inspiring and moving of others.

The anti-depressant

Lifting Life’s premises sat on quiet, leafy street. The closest major intersection had a pub, bicycle repair shop, and Vietnamese café, along with a few independent grocers. A small art gallery at one end of the road was being renovated at the time I started. A church stood at the other end. It had a choir that practiced regularly, and I often heard their warm, rhythmic vocals as I passed its open windows each week on my way to the group. When I was first introduced, the service manager who walked me through asked me if I had any trouble finding them since they were tucked off away from the main intersection. “No, not really,” I

replied, “It’s nice that you guys are here, it seems like a pleasant neighbourhood.” She nodded, “It is, we’re lucky to have found a home here. You know the grey building you pass when you get off the tube? There’s really not much there now... it used to be a hospice for people with HIV, but it closed down years ago, obviously... it wasn’t really needed anymore. Now it’s kind of an HIV advocacy place.”

Lifting Life had in many respects the same qualities of a typical support group. People would meet, sit in a circle, tell “their story,” speak about what difficulties they were experiencing, and listen to feedback and advice from their peers. It was however also very different in what it could offer, and on what scale, to its visitors. Over time, I came to see it more as a community centre than a support group per se. The charity worked out of a large, old, refurbished house, split across two floors. The house was donated by one of its original patrons. Over the past ten years it has gradually been modernised, with a series of open plan office spaces and IT stations, a restaurant style kitchen for preparing the weekly dinners, a large dining room, different sized reception rooms for holding workshops and clinics, and gaming and playrooms for children and younger visitors. The house had plenty of windows making it very bright and airy; its frames painted a crisp white and fitted with horizontal blinds.

Although the central team was small, it was notable for its active internship, volunteering and funding arms. On top of HIV management and health classes, it offered a hot meal, English language improvement, computer and IT introductions, yoga, massage and complementary therapies, counseling, and advice clinics every month run by solicitors and welfare officers. All of these services were run and

provided by a regular rota of volunteers who had particular skill sets, and professionals invited to come in for specific workshops.

I also later learned that the facilities and programs were unique in their efforts to assist adults, youth, and children, but they were limited to heterosexual men and women. The charity was set up to address what was seen as a lack of help for families affected by HIV, and to address HIV rates within heterosexual communities more generally, (given that support for gays with HIV had already been well established). The charity had approximately one thousand people registered in their database, but between sixty and a hundred would attend regularly each week.

The attention to perception was a recurring theme. As I spent more time there, I had the growing impression the facility was guided by a particular investment in matters of temperament, and mood. Staff and volunteers maintained a high level of cheerfulness: greetings were always enthused, with much smiling; hugs and pats on the shoulder were a regular feature of our interactions with one another and with visitors. Careful thought put into the décor and presentation of facilities. Walking through the main entrance, you were soon greeted with the scents of fragrant houseplants arranged near the main desk. A small potted orange tree and jasmine wreath sat amid lush succulents, flowering cactus, wispy ferns and trailing ivies. The kitchen window always had pots of basil and thyme sitting in front. The reading room was set up with plush armchairs and plenty of beautiful books about cooking, nutrition, travel, novels and memoirs. HIV and sexual health leaflets and guides were discretely stacked on a separate shelf. Colorful paintings and textiles hung on the walls, which were painted a gentle shade of pale yellow. The space was papered with colorful signage and messages, including Margaret Mead's famous quote,

“Never believe that a few caring people can't change the world. For, indeed, that's all who ever have.” Every week small vases of fresh flowers were perched in front of the windows throughout the premises.

Instructive feelings

Being loved

Relationships were probably one of the most heated subjects at Lifting Life. Relationships with partners, boyfriends, girlfriends, children, siblings, friends, colleagues, doctors, hairdressers, and the list went on. A great deal of attention was given to how the charity could help improve visitors' relationships in their everyday lives. There would be sessions on how to be more confident with one's HIV consultant and authority figures, but relationships on the whole were often approached through the issue of disclosure. Clients debated having HIV positive partners, or a partner who was negative, whether they had an obligation to tell, the risks of telling and whether one could trust the person or people you were disclosing to. For some, the consequences of disclosure would provide evidence: of that person's character, of the nature and depth of their love and commitment. The desire for loving and affectionate relations was not something people spoke directly to me about as a volunteer. In the group discussions, however, usually people were relatively open about past experiences and recounting of past hurts and disappointments. In one session on sexual health we had split up the women and men. One of the facilitators in the small circle of women I was sitting with asked them if they ever felt like having sex. There was a general silence, the other facilitator tried to fill the silence and prompted, “Maybe sometimes? When we're

feeling good?” One woman was shaking her head, and the facilitator nodded and said, “Yes, it is normal for some people to want a break from it.”

Despite visitors’ hesitations around relationships, how to say you had the virus in a situation of intimacy or friendship was something the charity prioritised in its guidance. Classes on disclosure of HIV covered questions such as when to disclose, what kind of reaction to expect, how to prepare yourself, and how to prepare others. Typically this talk opened with a few minutes of brainstorming. The service manager stood beside a flip chart propped up on a frame and asked people what they thought about when they heard the word disclosure. Volunteers sat with the audience, which had been broken up into small groups, and wrote down the responses as they were shouted out. “You’re only as ill as your secrets,” said one person. The manager nodded and replied, “Ok, so unburdening yourself of some of your secrets can unburden you of some your illness.” I remember I was sitting next to a visitor I spoke regularly with each week. She nudged me, as she was hard of hearing and did not always catch what was said. After I explained to her the expression the other person just used, she nodded and then said, “Well, even if you tell people, they say, ‘Oh I’m so sorry, I feel bad for you...’ But they cannot help, they cannot do anything or change anything.”

Another client in the middle of the room spoke up and reminded people that a lot of it had to do with time, she urged people to give others time to digest the news, accepting that they might go through a range of emotions. There were some who said they wanted other people to understand what they are going through.

The service manager nodded again, and responded, “Ok, so there is the possibility of raising awareness and understanding more generally through

disclosure?” One gentleman argued you could lose a lot by disclosing, others were similarly worried about being dismissed from their jobs. The service manager responded that as of 2010, changes were made to the law so questions about health and disability could only be raised after a job offer had been made. A few ladies said the reactions they had to disclosure were not as bad as they had anticipated, or not bad at all, and the individuals they told often showed understanding. Indeed, there were stories of children, colleagues and friends being told and people finding themselves embraced rather than shunned. One person volunteered, “We stigmatise ourselves.”

There were a variety of warming stories; the charity’s mainstay example though featured a real life couple that performed a role-play inspired by their real life experience. The role-play and emphasis obviously assumed visitors had partners or would, and could, have one.²⁴ In one scenario performed, the couple had been dating for two months and the one who is HIV positive is about to disclose their status. On this occasion he was HIV positive and she was negative. We are told she has never had any sexual health screening, but this is not something her boyfriend is aware of yet. He has just cooked her a French bistro style dinner and in the middle of the scene, the service manager tells him to pause, and asks the group audience how he should go about telling her. Suggestions included loading up on the romantic comments and compliments, or to start the conversation by asking her if she has ever

²⁴ Dating, though, was never featured in and of itself in the charity. Visitors often joked with one another and volunteers, and informally during sessions, about their dating trials, some even suggested the charity host more social events outside of the facilities so visitors could get to know one another better. The service manager often shook her head when these points were raised, saying firmly that Lifting Life would not get involved in setting up dating services. She said people were free to exchange contact information with each other, and could make use of dating websites developed specifically for persons with HIV. The pursuit of love was not something the centre was responsible for, though they did communicate the potential for it to happen.

had a general sexually transmitted disease screening. The couple then resumed the role-play. He started by saying he has a terminal illness. The service manager interjects again and asks the woman playing his date what she thought when he said he had a “terminal” illness. She said, “Well, I thought he was dying!” Laughter brushed across the room. The service manager said word choice was very important in these situations, and that “most people think of HIV as a chronic condition.” The couple continued with the rest of the scene. The girlfriend acts befuddled and he clarifies that he has the HIV virus. He assures her that he is on medication and that his condition is stable. He tells her he likes her and wants to be honest with her, and to let her decide for herself if she would like to continue their relationship.

After the role-play ended, the couple gave an informal testimony. In real life, he is negative and she is positive. She tells the group she disclosed quite frankly with most of the people in her life shortly after she was diagnosed. She did not feel she did anything wrong or that she had to be ashamed about. She told her now husband relatively soon after she met him, “I said, if he wanted to walk away, I would give him the chance. And if he wanted to stay, he would stay.” Her husband reached out his arm to take her hand in his and told the group they have a beautiful ten-year-old son and have been married for close to twenty years now. Soft cries and gasps could be heard around the room. His eyes were moist. The service manager stepped in again and reminded everyone that it was of course a very emotional issue.

A few moments later, the service manager asked if people had general comments. People suggested how the person reacts will tell you something about them; that it was important to know what you want out of disclosing and to not just tell for the sake of it; that the HIV positive partner might feel guilty about the risk

they cause for their negative partner; or the partner may have doubts about the HIV positive status because s/he does not “look” sick. Some people said they had to be careful as news and gossip tended to spread rapidly in the African community, with people talking about other peoples’ HIV status; some commented that they had successfully agreed with their partners to keep the information between themselves.

The couple has discussed their experiences in articles and newsletters, and was clearly comfortable with sharing their story. This “success story” was one of the charity’s chief examples of living positively with HIV. The interest in love relationships is not unusual for an HIV therapy group given the condition’s connotations of intimacy (and sexual relations) that have gone wrong. To use an analogy, work on diabetes has paid close attention to food, diet, and the ability to enjoy a “normal” meal. Similarly, the management of HIV seems acutely tied to the ways in which one is still able to have “normal” relationships. And importantly, an implicit message seemed to be how one is still worthy of those things, whether or not it was intimacy that people blamed for their HIV positive status in the first place.

Troubling emotions

Shannon and Paul were bereavement counsellors who carried sessions on managing difficult emotions. They handed out worksheets with different scenarios printed on them, and questions about how you would behave or react and how you would feel afterward. My group looked at me blankly and asked, “After what?” Shannon overheard and came by, “After having those feelings and that experience.” The puzzled faces remained but we carried on. The scenarios given had to do with a woman who has just been promoted at her job, and the second involved receiving a

letter from an electric utility company about late payment on a large overdue bill. Visitors had a variety of responses to these: one said she would be very happy about the promotion but also very worried about the new responsibilities, another remarked in response to the utility letter situation, that she would probably cry, be angry, ask “why me?” One gentleman said he would call the company about setting up an installment payment plan.

I glanced down at the worksheet; printed in bold is the question “how would it make you feel?” I repeated the question again to the group. No one said anything for a minute, then one volunteered, “I would be glad that I am getting recognition for my good work.” Her voice trails off. I could not help but flash back for a second to the icebreaker we had at the start of the evening. We were asked turn to the person next to us ask how their day was. I turned to one participant, Jennifer, and she said, “I don’t always like to show my emotions, I sometimes just say to people I want to be left alone.” The service manager later asked people if they used emotional language in their replies. Most people nodded, although many remained silent.

Shannon and Paul brought everyone back together to the slide show, which featured six universal emotions or expressions. They then talked about coping strategies. Paul stressed, “One is not better than the other. But usually it helps to just start with your emotions, say to yourself, ‘There are some things about my situation that I can’t change, but my feelings are there.’ You need to deal with those first, and then deal with the situation. Positive thinking has really helped me a lot personally. I don’t know how many of you know this, but there are scientific studies showing how positive thinking helps the immune system fight illness, how it strengthens it.”

Shannon opened the floor for general discussion. One visitor shouted out, “I get really angry about my status. I had a friend who announced my status to everyone on Facebook. You know, I got a thirteen year old daughter that I have to walk down the street with, and now this person that made me HIV positive is going around saying that it was me that gave it to her!” Paul nodded and replied, “Be with that anger – sit with it.” He paused for a minute, then said, “I know, here I am telling you to sit with your feelings but there are kids that need to get to school, groceries to buy...” His voice trailed off slightly. At that moment his microphone battery went out a little, he made a joke as he gave it a shake, “What am I feeling? What am I feeling?” Everyone laughed.

Learning relaxation

How visitors felt about themselves and their own personal situations was not something the group or staff could resolve. What Lifting Life could do was facilitate specific activities that delivered, or gave the appearance, of relief. I describe next the relaxation sessions that staff purported to be popular with visitors. I found these particular sessions, run by a hypnotherapist, to illustrate the explicit ways in which an interpretation of “wellness” was performed, where the self was less “monitored” than it was represented and solicited as something malleable.

Angela was one of the hypnotherapists brought in to facilitate the relaxation hour. The session usually started off with a flip chart. One question she often began with was what people did to relax. Reading, a walk, music, massage, bath, meditation, were some of the suggestions people gave. Angela flashed a large smile and added, “What about sex?” A round of laughter went around the room.

Relaxation was defined she said, “as a focused, intentional period of calm.” She then asked people in the audience what was important in their lives and what they cared about. Work, their children, school, church, were noted at the top of the list.

“What is the one thing missing?” she asked.

There was a long pause. She looked around the room, “Did anyone notice that the one thing missing from the flip chart was the “me?”? Most of you spend so much time taking care of other people, you probably forget that you need to take care of yourself as well.”

She went on, “Our minds can help or hurt us so it’s important that we do a bit of “brain training.” Your imagination is a power tool and it can create certain feelings in your body. Has everyone heard of the ABCs: action, belief, and consequence? Yeah? But did you know that emotions could also affect behavior and actions? The mind, and its thoughts, has the power to create inside you physical sensations and feelings.”

She had had us arrange the seating into a large circle around the room before starting. In the second half of the exercise, she asked everyone to close their eyes and take deep breaths in and out. She counted one as we inhaled, and two on the exhale. She counted up to ten. She asked us to continue to keep our eyes closed and to visualise a lemon, its shape, color, texture and fragrance. “Slice the lemon in half,” she said, “visualise its flesh and imagine its taste, the juice and sourness.”

She asked us to open our eyes after a few moments. Did people begin to taste the bitterness of the lemon in their mouth? The room was quiet but a few heads nodded. Following this, she asked us to close our eyes again, suggesting this time to, “start by picturing a lake: what shade of blue its waters were, if there were fish or

plants in it.” Next we were told to think of a place in our body that had tension, “give it a color you like,” she urged, “perhaps a golden yellow or pale lavender, and feel that color, imagine that color in the shape of an object, a ball for instance, and feel it slowly roll away from you along the water.” The room was silent.

“Keep your eyes closed,” she continued, “stay within the lake, and now I want you to imagine a ladder coming out of the lake, picture yourselves climbing up the ladder and slowly reaching the sky.” There was another short pause, a few people shifted in their seats, but the room was still quiet. Angela spoke again, “I’m going to slowly count to ten and then you can open our eyes again.”

“How does every one feel?”

People seemed still to be coming out of it and were slow to respond. One person responded that they felt a little drained. Another said that she was so relaxed she almost fell asleep. Another was choked up and wiping tears away from her eyes, “I’m sorry,” she said, “I don’t know why I’m crying.” Angela walked over and patted her on the shoulder, “I’ve done this exercise with a lot of people. The feeling of relief they have makes them realise the weight of the burdens they were carrying. Those feelings can be overwhelming.”

The insular feel about the charity was, it would appear, a feature of the haven it sought to provide. Staff, clients and volunteers were aware there were politically significant and sensitive debates implicating persons with HIV. The fact that this setting was used “to talk,” become informed and advised, on what were in some respects, traumatic matters, had a way of making the meetings feel closed off from everyday life and trials. It made the internal emphasis on inner well-being and relief all the more pronounced.

Medical anthropology has examined how people learn to be patients and negotiate what kind of patient they would like to be (Sered and Tabory 1999; Werner and Malterud 2003). To an extent, visitors' participation in the programs may reflect the very attributes of a "good" patient: one that seeks information and insight beyond hospital doors. Many of the sessions included the requisite worksheets and flip charts. But visitors were not guided solely in terms of their personal careers as patients with HIV. Inspiring positive feelings of affirmation and validation were also crucial, both as something made in relation to someone that accepts you, and as something conjured within one's self.

The idea of becoming an "expert patient" was a key feature in many of the health and wellness related workshops and talks I attended. Anthropologists and others have highlighted the varying constitutions of expertise, paying special attention to institutional knowledge, identities and objects (Carr 2009). For instance, as something that indicates proficiency of one's own condition, symptoms and needs, as well as something whose nature can be queried to explore varying forms and delivery of knowledge and authority, and the explicit and implicit dynamics of its presentation or articulation. Some supporting staff and volunteers highlighted potential weaknesses and lack of information amongst the visitors, which might affect their competency about the particulars of their medication and fitness regime's, and confidence when speaking with consultants and other "experts." One volunteer, who was doing a Master's degree in infectious diseases at a local university, expressed surprise and disbelief at how vague people were about their medication, "I couldn't believe some of them didn't even know what they were taking!" Providing information was perhaps one of the most common and obvious

aspects of any support or community group initiative. I did not, however, gather that the charity positioned itself necessarily as authorities or experts on HIV or social care.²⁵ I found the illustrations above compelling, though, for their emphasis on feelings and emotions *as sites of vulnerability*, requiring special care and needing to be “worked on” in learning to live with chronic illness.

The nature of hope in this context is somewhat blurred. Research on HIV as a global health epidemic has stressed the link between availability of and access to medication and hope for HIV positive people (Robins 2006). Living in the context of London, access to medication was on the whole not the problem. Participants did not highlight access as a difficulty. Hospitals and support groups obviously discussed medication as a necessary part of living with HIV, and the very reason that living with HIV is possible, but I also think activities and environments such as this one were suggestive of how dimensions of hope grow along many different horizons – material and emotive, for example, as a kind of belief and orientation, diversely vested in capsules, doctors, support workers, or relationships. Lifting Life, like Healthy Connection, had neither the capacity nor the mandate to change policies and laws on immigration, housing or benefits. It could lend a sympathetic ear, send out letters of support or persist with telephone calls - the limitations of which were often a source of frustration for visitors. Lifting Life was not unaware of this, of the constant disproportion between what they could do and what people needed.²⁶

²⁵ It directed its visitors to their clinicians, hospitals and social services for that, and in fact, should someone have a problem with something, they largely worked on a referral system and held the role of a *liaise*.

²⁶ During a post session chat, one of the volunteers recounted a problem one of the visitors was having with taking her tablets, she wondered if it was possible to have a ‘DOT’ (Directly Observed Therapy) arrangement set up for her. The service manager shook her head firmly replying that it was that person knew what to do, and it was her responsibility to take her pills.

The centre's gaps often seemed to be filled in with words and sentiment – like bits of moss growing between the cracks of a footpath – which maybe did cushion the walk along the way for some. Encouragement and being positive in attitude were important features of the facility's work. The popularity of self-help as a cultural movement is not unrelated to the equally favoured arguments about the health benefits of positive thinking. Writers like Barbara Ehrenreich (2009) have publicised what she finds to be potentially damaging underlying assumptions of these efforts, which ultimately place responsibility (and blame) on individuals for their problems. Critical research on cancer management preceding that on AIDS had similar arguments and critiques about the importance of individual will and belief systems for physical outcomes, along with the social rewards of demonstrating heroism and courage – of being a “survivor” (Jain 2007). Such a link was never pushed onto visitors, although some volunteered that it was usually their own secrets that made them sick.

The staff frequently reminded their visitors “be kind to yourself.” The affection and encouragement visitors were shown, and guided to show themselves, made me wonder if any of it could be considered as a kind of professionalised love and care. Love in this sense obviously moves in a different direction from anthropological studies of love in marriage and kinship relations, and their implications for health and welfare (Jankowiak 2008). The sessions looked at above flesh out an alternate dimension of the sociality of love, namely its mobilising as a defining feature of how one could take care of one's self. I found many of these workshops and sessions interesting for how they engaged the body whilst also venturing to mute it. The harnessing of words and thought process might appear to

some to be exaggerated gestures, with exaggerated results. To promote love and confidence in one's self as intrinsic to self-care and health may sound heavy with psychosocial pretense. At the same time, it would also raise the question of how and why thoughts and feelings come to matter, and if there is a renewed orientation toward them when there is increasingly greater attention on cultivating one's own sense of welfare and being well.

In the next sections I discuss another dimension of the making of therapeutic feelings that was significant at this site: the kind of sentiments and ambivalences generated in the encounters between visitors and volunteers, and the intimacy that takes shape between strangers.

Performing equivalence and therapeutic relationships

What else becomes viral via HIV? What else needs to be managed when strangers with HIV meet one another, and meet other strangers who are seeking, supposedly, to support them through a specific kind of, contact? The management of emotions and the exercising of professionalism are typical of caregiving environments and tasks. What was interesting about the relations and tensions here were the ways in which sentiments of working with "vulnerable" individuals unfolded along a continuum of ignorance. Volunteers knew something very intimate and private about the people they assisted, and yet had deeply fragmented glimpses into how their lives were constituted as persons and human beings.

Like many non-profit organisations, Lifting Life depended on a contingent of volunteers to maintain its weekly programs and operations. A small core of paid staff were responsible for the regular maintenance of the facilities during the week's

business hours, but it was typically volunteers distributed throughout the programs who had the chance to speak and socialise with clients. The volunteers were split between twenty something job seekers and students of public health and infectious disease control. Most were aiming to get experience in the charity sector or looking for ways to stay occupied while they looked for work. The main programs were typically held in the early evening after the workday.

In considering here more closely the thoughts and musings of non-clinical/non-practitioner volunteers, I recognise I am taking up a set of views which might seem quite peripheral, having neither to do with being a patient nor an expert of HIV or any other chronic illness. However, I have found more momentum and relevance in considering what the interactions and dynamics between extended staff and clients revealed, than in redrawing professional and lay divides.

Volunteers were encouraged to be activists and educators to the public, but there was to be no contact between clients and volunteers outside the premises – unless it was a greeting the visitor initiated. There were the usual professional precautions about not handing out mobile numbers or taking down personal contact details. It was not permitted that volunteers become “friends” and have social contact with clients. We were told it was because previously this has led to volunteers beginning to act as counsellors to people, and take on roles for which they are not trained nor obliged to do. The outline in our training packs stressed maintaining a professional relationship with clients, comparing it to a therapeutic relationship between a counsellor/therapist and their patient.

Volunteers were part of the charity’s “eyes and ears”, and encouraged to be observant of visitors’ behavior and interactions, and to keep an eye on anyone who

may require assistance. Each week, volunteers were allocated specific tasks or departments, this included buddying up with clients who have higher needs due to sensory or physical impairments. After the clients have left, volunteers were expected to gather briefly in one of the sitting rooms for a “recap”, and discuss how they found the evening. Each volunteer has a page in a large blue notebook to make notes of anything they felt needed to be recorded or followed up on regarding a particular visitor.

It was often during meal times and the hour leading up to the main session when volunteers had the most contact with visitors. This contact was stressed by staff as one of the most important parts of the evening as they themselves were not often able to chat with clients individually. And yet it was difficult to have sustained conversations with visitors. Conversations were frequently interrupted as different staff typically came around to ask volunteers to fill in and help with something on short notice. The search for things to talk about was also sometimes strained – many volunteers said they resorted to remarks about the food and menu that evening, or the weather. However, most of us were aware that these were not unusual challenges to volunteering in a large group. Margaret, a volunteer who recently graduated from her politics course, said to me, “I ask them how their day has been but people don’t say much most of the time. And most of them aren’t working, so it sort of makes sense. I think a lot of them are quite lonely, and bored. It’s sad.” Volunteers were sensitive to the fact that they were dealing with communities that were struggling with a multitude of issues, but we could only ever skim the surface of these tensions. The following is an excerpt from some of my field notes. This particular note has to do with visitors’ frustrations with food:

There is another person, Christopher, who comes most weeks. Almost always, the first thing he says to me is that he's all right but hasn't eaten in a while; this is his first real meal of the week. He, and a few others, have commented now and again, on how they think some clients get served more food than them, or get to have their second plate before others. Most people stay for the program, but there are some that come in, get their travel reimbursement, eat their meal, and then leave.

The reiterations of some visitors, even in passing conversations, were of course revealing on a number of levels. Christopher's remark about never really getting a chance to eat anything substantial except when he visits Lifting Life highlighted a basic struggle to keep his body going. Whether this was self-inflicted or what the underlying causes were, most of the volunteers could only guess. Many visitors passed through once or twice and I would not see them again. Christopher was a regular and I learned he had been staying at a homeless shelter for the past eleven months and most days he just had a cup of tea and some toast. I noticed he would often ask me, or one of the other volunteers, to fetch him another biscuit or a second cup of tea from the kitchen for him, although visitors were free to go in to the kitchen and help themselves to these things. On a train ride home with one of the interns, she suggested to me, "Maybe it's because he never has anyone to look in on him, sometimes it feels nice to be served, and have people get stuff for you, it's like, someone cares about them."

Whether or not volunteer gestures were considered themselves to be giving "care" was not immediately obvious. Another volunteer, Susan, working part time in a legal aid office, mentioned how she helped one of the visitors with some blisters she had on her toes, "I tidied them up with paper towel since they were quite swollen, and a bit of fluid was coming out of them, but they seemed ok." She did not

say anything about being uncomfortable and was very matter of fact about the task. She went on to say how another visitor sitting nearby advised this person if the blisters did not improve in the next day, she should go to the hospital. Susan shook her head a little at me, a puzzled expression on her face, “But they were just blisters.”

We were given basic guidance on what visitors were likely struggling with. But at the same time, the depth of these struggles, of what people were worried or upset about, was something our empathy could bridge only in a very narrow sense. These interactions were important to the conjuring of an atmosphere of care and consideration at the centre, but rarely did it feel like they brought people any closer together.

One of the issues that came up with the volunteers was the “invisibility” of HIV positive and negative statuses. Volunteers would occasionally report having slightly uncomfortable conversations that ended with visitors asking them when they were diagnosed – and having to explain they were not HIV positive themselves. No one at this site (or any of the groups I visited) be it staff, volunteers or visitors, wore any kind of identification. The service manager said to us multiple times, “That person [the visitor] knows the rules we have here. Everyone must be treated with respect, it doesn’t matter whether you have HIV or not. Everyone here is different, we respect each other in spite of those differences”. This “not seeing” of illness and seeing what appeared to be healthy,” “normal” looking people did not mean no distinctions were made – identifiers of race, nationality, age and gender, were no less present regardless of the HIV umbrella. What I want to stress for now is the degree

to which the emotive and communal effects and enactments of health and community were foregrounded, rather than the virus or disease itself.

Lifting Life was a “safe space” for persons with HIV. And volunteers were a part of that delicate fabric of refuge provided to people. The dynamics around the meeting of the normal and abnormal that Goffman (1963) outlined, were present in some respects between visitors and volunteers, but were also considerably eased given it was an environment where HIV positive status was known and shared amongst a majority of people. And if not shared, then at least experienced without worry of being stigmatised. My examples show something slightly different though from Goffman’s interest in relationships of difference, as volunteers and visitors were encouraged to connect not on the basis of who did or did not have HIV, but on the basis of shared feelings of understanding, and not knowing the particulars of one another in detail.

In an earlier chapter I looked at the ways in which group support was immersed in and gained momentum through ordinary and benign gestures. Lifting Life was not dissimilar from Healthy Connection given its emphasis on HIV as a chronic illness. This chapter has illustrated another example, though, of how community care functioned, showing an alternative to discourses and frameworks of surveillance that have become so popular in studies of biosociality and public health (Foucault 1978, 1980; Egan and Parker 2006; cf. Marsland 2012). It has considered how the insistence on conviviality and a positive disposition constituted another kind of discipline, albeit in softer form.

In her discussion of the politics of good feeling, Sara Ahmed (2008) has suggested “feelings” have become central ground for debates about the nature of public and private good. She points to how increasing emphasis on happiness and social cohesion has created a hierarchy of feelings that position some feelings as less progressive than others and thus requiring “conversion.” This goes for both representations of what makes a well-bonded nation and academic critique on the disproportionate emphasis on suffering and injury. She writes:

[...] this turn to happiness actually depends on the very distinction between good and bad feelings that presume bad feelings are backward and conservative and good feelings are forward and progressive. Bad feelings are seen as oriented towards the past; as a kind of stubbornness that ‘stops’ the subject from embracing the future. Good feelings are associated here with moving up, and getting out. I would argue that it is the very assumption that good feelings are open and bad feelings are closed that allows historical forms of injustice to disappear. [Ahmed 2008: 12]

Ahmed’s charge that the insistence on happiness and good feelings obscures the contexts and politics that may actually warrant bad feelings could likewise be raised here. What might be most unsettling about some of the material I have presented is how it depoliticises health and illness by making it a matter of personal comportment. Emphasising individual responsibility seems almost unreasonable amongst people struggling significantly with larger socioeconomic and legal battles, which are hardly to be resolved by one’s will power alone,. These arguments are well understood amongst most social and medical anthropologists. At the same time, this chapter has argued that, to a degree, a demedicalised approach to the body, demands we ask not only if this is a self regulatory technique in a new guise, but if and how the growing interest in self management efforts more generally, might be

invested in the relationship between the appeal of certain feelings, and renderings of normality, and if there might be a shift from feeling “normal” to “feeling good?”

In the following chapter, I explore in greater detail a case study that illustrates specific forgings of love and value of one’s self, and the significance (and ironies) of personal attachments for good feeling.

Chapter 5

“We live in a Barbie world”: self-fashioning, intimacy and performance

This chapter takes up the question of self and the functions of intimacy for both restoring and separating one's livelihood, how self and intimacy are framed, how they come together, though largely, it is interested in how they remain apart, and create more parts than wholes. The main argument is that they remain tenuous in that they are maintained through anticipation, constituted by forging beginnings and entertaining their “ending”: the second chance of another life, and the chance of a final breath, having a partner stay, and having them leave, or leaving them. I consider here three activities and narratives of self and intimacy that seemed especially relevant for one of my key informants, Regina. I take up 1) the careful attention she maintained in her appearance and her emphasis on “looking after herself”; 2) experiences of migrancy and having a place largely via the decisions of others; and 3) her investment in her partner and their relationship.

The title of this chapter was inspired by a telephone conversation we had. She called me one Sunday afternoon and declared, “We live in a Barbie world”. She had just come out of an incident involving a hospital reception staff member who did not want to book her in for something. Regina wondered if she was dismissed because her record showed she was HIV positive. She said to me, “It's a Baaarbie world – plastic world – if you don't like something or someone you just take it off and throw it away.” She also dropped the phrase “Lego-world” in the same breath. She then began talking about her boyfriend's obsession with his Xbox and violent video games, “He thinks he can just shoot people and shoot off their arms and legs.”

What she said about her boyfriend came into our chat rather abruptly. I suspected one situation reminded her of the other.

We had another phone conversation more recently, which also struck me with its entanglement of misfortune and dark humour. Regina had called me from a mental hospital she was put into after attempting a (failed) overdose with over-the-counter painkillers. The overdose had followed an argument with her boyfriend. As we were saying our goodbyes, our call was interrupted:

R. Nice talking to you, Dais...

D. Let me know how it goes... talk to you again soon...

[Bleeping noise in the background]

R. You hear that? That's the sound of this mental place, it's the panic button, but nobody is coming!

[We laugh]

For all the difficulty this conversation reflected, I could not help but find startling the levity of the exchange, and furthermore, what it said about how surviving and living are, sometimes, accidents. Debate about migrants with HIV in the UK frequently touches on issues of access to HIV medication and concerns about foreigners entering to take advantage of the health service. Charities and policy groups present counter-arguments demonstrating the innocence of migrants, pointing out how they become sick after arriving in the country, and suffer further in a legal and social system which is cruel towards refugees and asylum seekers. These are familiar arguments with a familiar set of charges and counter charges. I would like to ask, though, how might we put aside the "suffering body" and consider bodies that neither thrive nor survive, neither suffers nor lives without suffering? What does it mean to be considered an example of public risk, danger and burden, and on the other hand, to be confined and revived by trials of the intimate and private, such as having a home or love? It is this latter dimension I seek to draw out. Social research

on HIV is well acquainted with topics of love and intimacy. But if we can loosen those notions of intimacy away from taken for granted images of sexual relations and choices, I think we may have a better chance at exploring the breadth of intimacy. That is, broader sets of thought and feeling about having persons, experiences and objects in one's life that are emotionally meaningful, affirming of the desire for, and worthiness of, affection and attention.

Regina was born and raised in Botswana. She has been living in the UK for seven years, five of which without any formal identification or travel documents after her passport was stolen. She cannot remember her exact birthday. She has known of her HIV positive status for more than eight years, but did not speak of being on any treatment in her hometown.

Rather than reiterate she was HIV positive, Regina often said, "I'm undetectable, I'm undetectable." It came up sometimes when she talked about her and her partner not using condoms. She also observed people in the groups were often confused about how HIV test results were phrased, sometimes not realising that having an undetectable viral load did not mean they were negative. Regina came off to me as neither defensive nor proud. As I came to know her better, I felt myself drifting away from seemingly much more urgent, and quite sociologically amiable, questions seeking to gauge her "attitude" toward her medication and her "health." I became less keen on dissecting her "behavior" than I was in grasping her sense of place, and being, in and with the world.

I have invested more in Regina's words and articulations to an extent because those were things that I could have access to. I have kept close to her words, mostly because talking was one of the few acts and activities she too could access, at her

own pace, without making too many sacrifices and compromises. I accepted what she assembled for herself, and have tried to reassemble her reassembling here.

“I look after myself”

Regina’s convictions often matched the intensity of her despair: “I love myself too much!” and, “Better just to go home and die peacefully,” were two statements I heard at different points of field work. She occasionally rested between these two phrases, traveling frequently between them. She was a spectrum of expressions: articulate, reflective, and motivated, with bouts of depression and low mood. The outbursts of advice and opinion she gave were interspersed with pauses and quiet. Her speech often roared ahead of her, like a speeding car leaving in its wake dust paths and engine smoke. I recorded her frequent stammers as I heard them. This was not to crush her eloquence, only to appreciate the speed and rushes as symptomatic of her passion; and perhaps also of her circumstances, which demanded she reiterate her story, her condition, to counsellors, support workers and the like; and not least, as reflective of the cyclical frustrations with her partner. The sentence or word lying on the road, on its side, before the next word or sentence started, the jerks and pulls of her narrative gave it its own beat: as if her mouth could not empty out the words fast enough, they pushed one another over and pushed their way out. Her hybrid expositions were a cross between motivational speaking, gospel charm, and lamentation.

She was an expert on a lot of things: HIV disclosure, hypnotherapy, the mutual idiocies and graces of charitable organisations, marathon training, and gardening. The world of teaching people how to manage their HIV is saturated with

encouragement to love, and be kind to, one's self, above all. Regina was not, however, a typical HIV "activist": attending conferences, sharing her story, and publicising the condition in the media. Her wanting to demonstrate style and personal initiative seemed to have little or nothing to do with having HIV.

The theme of another chance at life, and finding love for one's self again, assuming it was lost, provokes more interesting questions than meets the eye. Regina's HIV positive make her actions seem particularly poignant: looping a string of fake pearls around her neck, quietly resisting social stigma and shame, one strand at a time. But I was reluctant to cast her efforts as resistance, as a deliberate attempt to overcome her condition. If there were elements of camouflage, I wondered if it might have had less to do with disguising her illness than exercising control in ways that were within her reach. Now and again she made remarks about cover, disguise, and staying hidden by not standing out as ugly and dirty. What interests me is her insistence on putting a very particular face and appearance to the outside world, and how self-care presents as asserting taste whilst sensing the gaze of others. Regina's character, ways of speaking and living, quickly complicated any familiar questions about self-care that I had grown comfortable with. I consider in the following paragraphs some insights I gathered into Regina's self-presentation efforts

During one visit, we were sitting inside her boyfriend's studio. Regina, James and myself, were perched on the side of the bed, which doubled as a sofa. Across from us was an acquaintance of James's who sat in the folding plastic chair. Regina had said earlier as we came up the stairs that James met the woman at a day centre and offered to help as she did not know many people and was struggling to find a place to stay. So today, she stopped by. She spoke with a faint accent, east

European perhaps. She did not give a name. Five cigarette ends lay curled in an ashtray beside her. She either looked out the window or glanced at the television below it. Her eyes had a faraway look in them. She said to us after a few moments, “I was sent to this one place, but it’s for crazy people, [she gestures at her head], so I left.” Regina asked me if I still had on my phone the details for the women’s emergency shelter I recommended to her several months back. I went through my messages and said I did. I showed the lady the details and she wrote them down in block letters on a piece of scrap paper. Regina explained to her the shelter’s protocol, “When you get there, just tell them that you have nowhere to go. They will give you a starter pack with rice, beans, and tinned fish, that kind of thing. There’s a separate sitting room where you can watch TV.” The lady shook her head and gave a smile to Regina’s boyfriend, “James, Regina has a lot of energy!”

Regina got up and went over to the counter and put some chocolate biscuits on a plate for us, saying to the lady as she did so, “I look after myself, I don’t drink, I don’t smoke.” She sat back down and held the plate out to her, then me, then James before taking one herself. We sat in silence for several minutes, listening only to ourselves chew on the biscuits. James got up and put his jacket on, said he had an appointment to go to. We said goodbye to him. Regina switched on the television and the program Antiques Roadshow was on. She settled back on the polka dot cushions on the bed, swung her legs a bit, and said, “We’re sitting in my lounge in the country!” She kept her eyes on the screen, “Back home, when we were kids, we’d be watching a TV show and we’d say, I’m sitting in Pareeeeeeeee!”

Later that evening, Regina and I spoke on the phone. She said she and James had a fight, he was annoyed with how she had acted that afternoon, “He said he

didn't understand why I had to be showing off to the other lady. "I wasn't showing off, I said to him, "I was just giving her the information, and saying that I take care of myself. I look after myself, I don't want people to look at me and say she's got problems. If people envy you that's a blessing – it becomes your choice if you want to tell them about your problems."

Regina's confidence may seem slightly unusual, given how fragile her own position was. But it was because her situation was fragile, I think, that she made a point of asserting herself, her style. I knew she had a small circle of professional personnel she consulted: HIV doctors, nurses, nutritionists, and psychologists. She did not say much about her HIV physician but spoke of her psychologist a number of times – the meetings they had, what she's advised her to do in the past. She was getting her HIV medication and on good terms with her GP, "All the people who go to the GP I go to, they are all drug addicts, so I'm normal, I'm a good one." She laughed and shook her head.

She was a "good" patient in other ways: purchasing the healthiest foods she could, walking frequently for exercise, not smoking or consuming alcohol. Getting the food she needed, though, was usually a compromise. One time we had come out of a meeting about healthy eating on a budget. She had been trying to explain to people that the voucher she relies on could only be used during certain store hours. One lady in the audience shouted out to her that she would give her 5 pounds for her 10 pound voucher. "How does that help her?" another client asked. "So she can get the cash!" the lady shouted back and shrugged. One of the group leaders said she did her shopping near closing time, when they start discounting items. She tipped her chin up slightly, "So – I get to have my organic eggs."

Regina sat back in her seat on the bus, “No one was listening to me, if I buy Activia yoghurt, I can’t get my chicken. The good stuff, the food I need, costs more. If I get one thing that fits, I have to cut back on buying another thing which I also need for my diet.” She was annoyed that her voucher could only be spent at one chain of supermarkets, “I could buy so much more if I could use it at one pound shops.”

Her sense of compromise worked well for her though when it came to her ability to stretch a pound to serve her love of fashion. She would often treat herself at charity shops. The clothes were inexpensive and she enjoyed doing the odd bit of sewing if she felt they needed a little creativity: cutting off sleeves or collars, attaching ribbon and trim, fabric flowers and bows along the wrists and neckline.

“My stuff is all over the place,” she would say, “I’ve left some stuff with friends, at my boyfriend’s hostel, everything is everywhere.” Regina did not have a fixed address, and lived on and off in a couple of different places. She kept her pajamas folded up in her handbag. I visited her at the small hostel room on one occasion and saw it was packed full up with both their possessions. Pink suitcases were stacked on top of the wardrobe by the sink, more bags and boxes placed underneath the sink and on the shelf by the door. I think she had accumulated most of London’s best secondhand buys: black and red platform shoes, form fitting denim, endless dresses, some covered in lace, some covered in rhinestones, brightly colored jumpers, leather jackets, patterned tops, a huge assortment of accessories were piled high in one corner, a rattan fedora, handbags, sunglasses, red net stockings, beaded necklaces and more. “I gotta stop buying clothes,” she said, shaking her head, “I don’t have the space.”

We spoke as she was putting a bag of things together for one of the younger visitors to the group. “I like giving things to Agatha,” she said to me, “She is the baby and the others are always bullying her. She had come up to me before and I noticed her skin was rough, and that her clothes were boring. I told her, ‘Use this face cream, and dress nicely, so the others don’t push you around.’ Her face is starting to look a lot smoother – and she told me she’s got a boyfriend now.”

Regina picked a dark blue skirt from her pile, opened it and held it out in front of her. She went on, “My looks are important to me, I have to look good. I *have* to look good. I have to look nice. Every morning, I have to think: what am I going to wear? I can pick it out and put it there and put it on and decide five minutes later, oh I don’t want that! My legs look so big in it. I don’t like to look big. I’m too short to look big!”

I nodded and helped her fold a few knit skirts. I asked her if she remembered the day we first met – what she was wearing, what she said.

The city had hardly begun to thaw. On that night, the air was cold and the traffic still roaring despite the late hour. We spoke with our hands buried in our coat pockets, chins tucked into our scarves, stamping our feet now and again to keep them from going numb. Before I learned or recorded anything about Regina’s background or life history, and even after, I remembered her faux fur coat – hazel brown with metallic gold buttons. It had a high black collar turned up halfway so it trimmed her chin and jaw. The coat hung over her shoulders and fell past her knees just enough so it would have appeared too big for her – if she did sit up straight. It was like she was sitting in a large, high backed armchair. But it was the coat that seemed to be holding her up. A purple satin headband with a single flower wound around her

head, the small flower resting crookedly on the side. Pearl earrings were clipped to her ear lobes. She blinked at me through thick red-rimmed spectacles. Her smile spread like an ivory paper fan opening.

She had been speaking of her boyfriend. “How long have you two been dating?” I asked. “We met in June,” she said, “and we started going out in September. A lot of people in the groups, they have come up to me and told me I looked different – that I looked better.” “Why’s that?” I ask. “It’s *love*! When you’re feeling good your body makes happiness hormones.” I laughed out loud, “Happiness hormones?!” I repeated. “Yeah, yeaahh, yeahhh,” Regina said. “Ever since I met James I’ve been feeling happy.” Regina paused for a moment, looks at a car that pulls up to the corner where we are standing and a lady gets out, wearing rubber boots and a coat over what look like pajama bottoms. Regina peered over the rims of her glasses, shook her head, and muttered, “This is London? Where are the clothes, where is the fashion?” We spoke for a few more moments when her phone started to ring. It was her boyfriend wondering where she was and when she was going to meet up with him. “I’m talking with a friend from the group, dear... can I call you back?”

I asked her as we finished up Agatha’s parcel, “Do you remember that evening? You wore that fur coat. Remember how someone from the group complimented you on it. And you were like, ‘Do you think I want to look like I have HIV?’ Do you remember?”

“Yeah, yeah,” she nodded, “He bought it me for Christmas. Who would want to look like HIV? Who would want to look like a homeless person? No way. Not me.

You know, I've got nothing, except for my respect. When you are stripped, you hang onto things – there are things that... I'm more, like, my looks.”

She pauses, jingles a few brass bracelets. “I just – I don't want people to read me by my cover, you know? I'm undercover. So I have to look dressed like a – like an undercover person, you know? I'm living – I'm living a false lie, because I've been living a false lie all my life, so I have to make myself look—I don't want to look like my problem. I want to look like someone who's got it *all*. That's why, people look at me – they get so envious. [They say] ‘She always complain, but she's got everything!! What does she need fund – fund fundraising for? What does she need begging for? Look at her.’”

Looking like HIV and a homeless person, here, was clearly tacked onto images of looking dirty and unkempt. But to look too polished, too fashionable, that was also inauthentic to some of her HIV positive peers (Malkki 1996). Regina wanted to draw people's gaze to how she had fashioned herself, almost as an act of defiance, “I'll surprise you, and show you that, you, not telling me what to do. You know, we go shopping, and people, like, say, “Oh that couldn't look nice on you.” I'll take it, and I'll wear it. You tell me that won't look nice, but I will wear it. Sometimes, I take things off because James says, “Oh you don't look nice in that.” I take it off. But next day, he sees me on it, and says, “You looking good!” She laughs. I said, “You have to work around the dots.” I got this from—where did I get this?” [she looks down and pulls at her black t-shirt printed with grey skulls] “From the rubbish bin! Yeah, I got this from the rubbish bin, I think someone throw—so I thought to myself, hmmm rubbish bin... I took it, I gave it to him to wash, I put it on and he liked it!”

Regina folded the skirt and put it to one side. She walked over to the cupboard and took out some blouses, laying them out on the bed and chair, looking them over. She held up one floral blouse with a purple collar, “They mustn’t care—they mustn’t—you know, what we do, we are models – we’re a mould, mould of people, - moulding, we mould people, society moulds us, in a way where it’s not good for all of us. Because, money, can mould people with money in a different way from people who don’t have money. So people who don’t have money need another... technical way... of model. So — I don’t need to look at Kate Moss for a role model, I can look on someone who came from the dust and worked herself up. That’s my role model. I have to look for someone who came from where I’m at. That’s the person who will be my role model.”

Regina’s analogy comparing socioeconomic categories and classes as moulds and castings literally shaping bodies and lives, communicates clearly how she thinks she is positioned and, and what inspires her not simply to reflect back on, but to resist, her impoverished beginnings.

She folds the blouse and sets it on top of the skirt. She leans down under the bed and comes up with a pair of black heels. She opens the cupboard again and takes out a black suit jacket. “Kate Moss is not my role model. And what’s his name? That Bill Gates, is not my role model. No, no, no, I need someone who didn’t go to high school, and say, *look*, I did that, I did that, I did that, I did that. And *that* person will be my role model. And I haven’t met one.” She put the clothes, shoes and jacket into a shopping bag to bring with her to the next meeting to give to Agatha.

Cocoons

Kate Moss was a popular reference for Regina. She told me once she felt her morals were stronger than the supermodel's, and she had explained her logic to James one time when she was angry at him for stealing from a shop, "You know, you look at Kate Moss, and her values, and you look at me and my values, who's got more values? Her or me? I struggle for what I give, she doesn't, she just *pose*. She got looks. She just got lucky. That girl was very lucky. She's not beautiful. She's just one of the lucky people."

Regina and I had just finished a late lunch at a local pub near the shelter where she had stayed several weeks back. She had a bacon and tomato sandwich. I had some soup. Our meeting had been scheduled for two hours earlier. I arrived and waited, thinking we might have missed our chance. I finally received a text from Regina. She said she had been sleeping. She slept through her alarms and all her phone calls and messages. She had taken some tablets earlier to help with pain she had been having in her legs. The tablets wiped her out.

Elton John blared out "Your Song" from a radio in the corner. Regina looked up for a moment, and said she loved soft rock and would tune into this same music station on the television at her boyfriend's place whenever she was there. I asked her if she wanted another coffee and she paused for a moment, checking her phone. She glanced at her nearly empty cup and said ok. I signaled to the waitress that we wanted two more coffees, a black and a white. A few moments later she set the beige ceramic cups and saucers on the table, the bracelets on her wrist hitting against the sides of the cups lightly as she did so, making a clinking sound.

Regina made a few rapid clicks on her phone's keypad, and pushed it aside, next to the plastic bottle of ketchup. She pulled the cup toward her, looked at it, frowned, and said there was not enough milk in it, "They're always so stingy with the milk." She walked over to the waitress and told her she needed more milk. When she came back, Regina reached over to the small square dish holding an assortment of white and brown sugar, and pastel packets of artificial sweetener. She gestured toward the container and I shook my head, saying I liked my coffee black. She ripped open five sachets of white sugar separately before tapping each one into her cup, mixing the milky liquid briskly with a teaspoon. Her fur coat rested on the back of the chair next to her. "That was the meanest thing he ever did to me, you know," she says, rapidly stirring circles into her coffee, "giving up that house they offered him."

I remembered she said she had been sleeping under someone's desk. She would also occasionally camp out in the sitting room of a pensioner friend. A warden watched the residence between eight in the morning and four in the afternoon. She left at five or six in the morning each day to be safe. She had been working for the pensioner as a casual caregiver and cleaner for about four years, "I treat him with dignity, I don't have special degrees or qualifications but I treat him with respect. The nurses wanted to take credit for my work, but the patient told them to go away. Now his garden is nice too – people pass by and ask if they can see it!" She said they occasionally squabbled over her not paying rent. But she also remarked that she did more for him than his own children did, ensuring his flat remained tidy and giving him cards during the holidays.

Regina had her highs and lows. When she had her lows, she talked about luck, saying to me, “Maybe I’m just not lucky.” She elaborated more on her feelings about how her life was in Britain, speaking briefly of what sounded like a relatively bleak and unlucky upbringing back home. She had a grown son back home but in general spoke little about her family. Of her siblings she simply said she had many sisters and brothers, but they all grew up in different houses in Botswana and were not close. Her mother had to work and dispersed them across the township. She did not know her father well, only that he was from Tanzania, and she did not consider him her father.

Her eldest, a daughter, died the day she was diagnosed with HIV. And there was another outside marker highlighting that day for her in more ways than one: her diagnosis also happened within a few days of the September 11 attacks in the US.²⁷:

D: When – did you know you were sick?

R: Yeah. I know I’m HIV, that’s why I wanted to travel before I die.

D: When did you find out you had HIV?

R: I think... 1999... same time that the uhh... American tower... the same week actually... the same... just few days before. The same. Before [it] happened, I was sitting in bed, and it gave me enough time to fucking cry, I screamed like I was screaming for – but I – In a way I wished – I was so *envious* of those people jumping. I thought I was – I *wished* I was there.

D: Jumping out of a building?

R: I wished I was the one who was jumping. Yeah. And I felt... I was so angry.

²⁷ These details, dates and events, came to me at different points in time and conversation, I was not sure if the dates were “correct.” All I knew was that I gave her the benefit of the doubt, not out of pity or friendship, but because I began from the assumption that the different layers in her biography did not need to be verifiable in order to be revealing and insightful. Whether her memory served her accurately or not, there was no way she nor I could check. Either way, it would do little to rectify things in her life, or alter the value of our conversations

She paused. The started again, “Botswana's not what people – that's why the [UK] government thinks Botswana is well off. Botswana is well off for the rich. But for me, I'm in an island, I'm in a desert, I'm in – I am in my small boundaries, really limited. In my cocoon. I'm in my cocoon.”

Cocoon. That was another word she was fond of. Sometimes Regina would joke on the bus about having to rush back to her boyfriend's hostel to eat the dinner she prepared, in order to be back at her pensioner's building on time, “my cocoon!” she would exclaim. At other times she would be remembering how things were for her when she was young, “they [the British] *took* my wealth in my country, they controlled my country, they put me in a cocoon. I was not human enough in my own country [...]”

Shortly after she was diagnosed, an acquaintance of a friend offered her a job to work as a nanny as they were traveling to Britain and required someone to take care of the children. Regina's plan was to travel and then “go home and die peacefully.” She had been given a six-month visa. However, after arriving in the UK, she had a falling out with the family she worked for. The woman she came with also stole her passport and refused to give it back. Subsequently, she was not able to renew her visa and overstayed. After arriving in Luton, she said she found some leaflets at a local library, advertising HIV charities and support groups, and started attending and gathering advice. A white South African she met at one of the support groups informed her she would be able get her medication, and that she should consider staying, that she would be silly to go back.

I asked her how she found her way to London. Her eyes gleamed. She replied, “You know I used to travel on a deck? On the—on the bus, on the double—

the top deck—on the opp—deck, on *any* bus, I used to take *any* bus, put 10 pound, when I get my money ... and *travel*.... the *whole* day. And the old lady I used to look after, she used to get annoyed! But the view at night, London is *beautiful* at night, [whispers loudly] *beeauuuuutiful*.” She stirred her coffee again, smiled, and glanced out the smudged windowpanes.

A few minutes of quiet passed as we listened to the radio and sipped our coffee. I took another sip and put my cup down, “What was it you were saying before about how it didn’t work out – that place you were staying at over Christmas?”

She looked at me, shook her head and sighed, “They wanted to send me to fucking *Luton*.” “They” was the charity she had called to see if they could arrange accommodation for her:

[...] before I even left the hospital, I told the staff, the night shelter, I *told* her, I said, “I’m getting sick, and I can’t sleep in this place.” And I had to ask permission to come to the evening group, because you have to be back at the shelter by 8. I told her, and every time, I said I have to explain myself at the door because they won’t let me in – because the guy who was working yesterday didn’t let the other guy who was working today [know]. Because they all volunteers. They all do their own thing. And I told her, and she didn’t—she [the charity manager who arranged the bed] said “Ohhh”, I said, Yuh, it’s a big hall! The only thing that separate women is the thick cardboard, you can hear them when they turn around on the other side, they smoke right there, and the door is open, and the smoke – the—the wind blows—right there, it’s freezing, the ice, the snow—the snow is so thick outside. And I ended up in hospital.

And I was shocked when she told this lady [the charity manager’s intern] that I refused the first place. And when she [the intern] phoned the second time, the same place, and then she asked me, “Should I disclose your HIV?” I said, I don’t know how your boss did it the last time, and then—and then I said, “If it won’t make any complication, you can tell them, but if it does, I don’t know I don’t know, you the one that’s dealing with them. I don’t know what they accept.” And there was a bed for me. And when she told them I was HIV – they closed the door.

The *same* shelter that accommodated me [before]. Because the guy [who worked at the shelter], the guy that I—because, what I did, I spoke to them before I left, I spoke to them [about coming back], so the guy said you can, just call us if you come back again. They wouldn't *find* me in the registration [the second time, after hearing about my status], that's what the lady said. I was not even in the registration. And I knew she was lying.

[sighs] She asked me, “Should I tell them?” I said you the one who's dealing with them, I don't know the situation, you – because I trust her to deal with it. And then after she told them, suddenly now they saying they fully booked. But 5 minutes ago when I spoke to them she said there was a room, there was a place. And now they turn this around, and say they close the door because I didn't stay there, I didn't go the last time. I said, no, I *did*, I stayed there the whole bloody month actually! I stayed there the whole bloody month. December, December, January. December.

Even... I didn't—I didn't just leave—I didn't I—I—I spoke to—I spoke to the guy in the shelter, I said, someone is accommodating me for 3 months, I said, this 3 months I might gonna come back. And the guy said, no no no problem, people come and go here, as long as you leave in a good manner. And because I didn't want to take the other place, I don't have anybody there [in Luton], if I get stranded there, who I'm gonna cry to? And it was only for a weekend. Because this is what they do, when they don't know what to do with you, they send you *far* away.

She tugged at her orange scarf, and started ripping up a paper napkin into strips, and rolling and twisting them so they resembled paper roses.

And—and because, I think, they judge me on how I dress myself... they think I'm rich, because even my psychologist said to me, “Oh, you could—could be saving your money, you always wear this expensive—” And the bag was only 5 pound! And that—that is discrimination coming from a professional person. I found this. In my face, “You always turn up with nice things.” I said, most of these things I don't even buy them, I got a lot of things from Crisis—Christmas—some of them they have new. At the groups, people bring stuff, some of the things are new, I get.

If my boyfriend feel like he want to treat me, it's his money he can do whatever he wants, I'm not his responsibili—I'm not his priority—you know, this thing can fall off—fall apart any time. And I was, like, annoyed about it actually. Like, ohh, you—you—look at how you dress. And I'm thinking.... do I have to dress like a *rag*, and show myself like I'm—and my boyfriend said to me, “You better stop dressing like you—like you own a—a 6 bedroom.” I said, “I'm not, because it's not in my nature. If I can get a nice, expensive dress for 50p in a charity shop I will go for it.” I'm not looking for

sympathy here. I'm just looking for help. Just a little bit of help. Not sympathy, you know?

Early in her relationship with James, Regina said some people would sometimes make snide comments about how or why someone would want to be with her. She said she told them, “I don’t want to be alone”. However, it seemed her thoughts and intuition always seemed to sense how easily her anticipations and joys could crumble, “I don’t—I don’t want to be on my own but I feel my life is gonna put me in a place where I’m gonna be on my own.”

Regina’s “place” and appearance were often assumed to “fit,” or *ought* to fit, together, by many of her professional and personal acquaintances (Malkki 1996). It was important to “look” the part she wanted to play, to get the help she needed. The two were clearly in contest much of the time. By all accounts she was encouraged to take care of herself given her medical condition. But being well and looking well were not as simple to achieve, particularly if one was expected to demonstrate how much in need they were to potential sources of support. Even those pockets of expertise and compassion Regina attempted to engage, failed to acknowledge her vulnerability as a matter of social responsibility, over that of individual deservingness (Willen et al. 2011).

Charity and being loved again

I wish there was someone up there who can just sponsor me. And get me out of this shit! [Laughs] It's not about love, it's about life – my life is not—with him, I will be—I'll be happy—but I won't be... like... spiritually happy? I will be like, uh, like uh, I'm just here for the sake of being here. I won't be here [claps hands], life just began! Life doesn't begin to me, I'm just happy because I just, I walk extra mile. It will be about that little extra mile, not about me having my life back. It's not about me having my life because I will still be fucking [claps hands] living *his* life. [Excerpt from interview]

We were standing in her boyfriend's room. She had her hands tucked in her jean pockets, "Because I grew up in a slum, it made me *curious* about things." She showed me the collection of small toys and figurines she has accumulated over the years, fetched from various charity shops and rubbish piles. I scanned the Disney characters, rabbits and farm animals, and picked up a small porcelain box with a pretty design on it. It was painted gold on the edges with roses on the top, a leaf design curled around the sides. "That seems unusual," I remarked, "the design on the sides." I look under the box. "It says King George XVI," I said. Regina's eyes widened, "I'm going to look that up, you know it could be antique, these things, people just throw them out and you pay 10p for it but it could be worth 10 000 pounds! You know old things, they were built to have a *life*, not like all these things they make now where there's an update every ten minutes – and then what you've had is old and has to be thrown away."

The toys appeared a useful distraction. She said she once said to James, "'I deal with my problems by buying junk.'" She said she was trying to make a point with him: that her way of dealing with her problems was less harmful than his way of dealing with his, namely, with recreational drugs, alcohol and casual sex. She held high hopes that she would be able to resell her charity finds for a profit one day.

Regina said her and James had met at the GP's office while they were attending the same surgery. His personality, behavior and activities were a constant source of anxiety for her. Being a regular fan of hard cider, marijuana, and video games, he had his own health and social history to reconcile. There was never a clear separation between her love for him and anger at him. There was never a clear separation between their relationship and the matter of finding legitimacy in the UK:

R: Yeeaah... my life *taught* me that: *to fit in*. Try to fit in as much as possible. Make myself comfortable. I won't put myself in a situation where I'm not *happy*. Even if it's a... fucked up situation. If I'm not happy, I wouldn't... put myself in that, but if I'm happy, with a fucked up situation, that's me.

D: [I nodded] Right.

R: I'm in it. [Chuckles]. I'm happy. Because I know, I'm in control.

D: Right. Ok.

R: My situation now: I'm not in control. James is in control of my life. That's what *makes me mad*. I don't... I'm not used to... *beg*... I'm not used to *bow*... I'm not used to... I'm used to say, "Ok that's how you want it, fuck off, this is me."

D: Yeah, yeah, "I go my own way."

R: I go my own way. But now, my corner is so tight, I don't have options, my option is now... because he's willing, and he's accepting me, I think because he accept me, with my condition, with my—umm, problems, I think that's the only thing that makes me *stick* with him, because he *accept* me for who I am. [Pause]. I'm not happy. He's not the best man I would pick in my life. I even told him, I said "You know, if I was not in this situation, you would be last, you would be the last person... but because I'm in this situation... It's not about *choices*. I don't have any choice; my choices were gone, years ago. I never had a choice. Now I...

I struggled with how to untangle her remarks. Being HIV positive is for some the ultimate test of true love in a potential mate, particularly if that person is negative. However, Regina felt she was the one making compromises for James. She said her body was strong and her CD4 count was high. But this has not stopped her from reminding her boyfriend to use protection if he decides to sleep with other people. She said any tests would show straight away if he infected her with something new, "My condition makes me more vulnerable than *him*."

R: I don't even have a choice nowadays. Even when people say, oh why don't you just, you know, at least you gotta home back home. I said, "Is that what you think I do have?" I said, you know, don't look at your situation and look at me and think if you can do that, because you can do that, I can do it. *There are things that I can't do*. There are things that... even if I want to, I can't do... because of... situations. Going—back—there. What am I going back for—what do you, what—what, what is the difference? What makes—what will be—what will be happen—at least here I'm getting my medication. When I came here, I was not on med—I wasn't qualify... even when I go

back, I won't qualify for medication because I'm undetectable. I'm undetectable, so I would *lose*. I would get sick.

I noticed Regina would refer to her HIV as her “condition,” rather than saying for instance, “Because I’m sick.” The word “sick” typically came into our chats as a metaphor for exasperation, emotional exhaustion, frustration and being depressed. When we talked about special books and guides for persons with HIV, she would say, “I’m sick of it, I’m sick of things only being for HIV people.” Her body had its aches and complaints, high cholesterol, increased appetite and weight gain that were common side effects of HIV medication. Or if she felt flu-ish or like she was about to catch a cold, in these cases, she would say something about being “sick.”

One of the first statements Regina made to me when we first met was her insistence that HIV was not killing “us,” (I gathered she meant the group, community, other migrants), but that “immigration was killing us.” Later, in the interview, she reiterated this point using different words, underscoring the cutting reality of making a new start largely defined by what it excludes:

When I first got here, I felt home, I felt at home. The problem is – this is the problem: me, without law, I'm at home. [...] Without the rules and regulations, I'm ok. But once the rules start coming [deepens voice]: you HIV, you can't be looking after children. That's when things start kicking in my head: ohhh my God, ohhh you don't have papers, you're an over-stayer, you not supposed to be here, you getting medication in this hospital, you're not supposed—things like that, they are the ones that messes me [...].

Entertaining biological vulnerability was the more immediate and clarifying activity, and she confided freely in her doctor. She had sought legal advice early upon her arrival, and said the responses had always been the same: Botswana was considered to be a far better place than before for persons with HIV, and she would

be sent back. Regina's corner was bound by rules and regulations. The Law, with a capital L, loomed well and large. She spoke often of how James would push "the immigration thing", "But I said to him, you not feeding me, or housing me, or supporting me, nothing. So this has got nothing to do with immigration." She would sometimes say things that made me think their relationship was purely practical, ("The only reason I'm sticking with it is because I need a place to stay" or "If I could find someone to sponsor me I would have left him long time [ago]"). Plain survival. And then there would be what appeared to be forms and objects of love between them.

One late afternoon on a rainy Sunday, Regina and I were completing a walk around Covent Garden. She loved home decorating shops. We spent some time admiring a large mirror ringed with pieces of beach wood, and a paper chain with butterflies cut into it, draped around a blue chandelier on the ceiling. Her boyfriend met up with us, as we were finishing up. He had just come from a mobile phone repair shop. "They said they couldn't repair it," he said. Regina asked if she could take a look at the phone. He shook his head and said, "What for, hon? Never mind, it's still broken anyways." He then said he had to get something and would meet us at the bus stop. Regina turned to me, "You see how he is? Won't even let me look at his fucking phone even though it's broken."

The rain was really starting to come down. Regina opened the little red umbrella she had tucked in her purse. We huddled underneath it, peering now and then down the road for my bus. We saw James walking towards us, his white t-shirt beginning to get soaked through. He grinned as he approached Regina. He reached into his trouser pocket and pulled out a small mirror compact, "Here, sweetheart, I

gotchu something.” It was round and pink and had a small dove painted on the front, tucked in the dove’s mouth was a little envelope. Regina smiled, “Awwwww, thank you!” She held the mirror in her hand for a moment, and then flipped it around, saw the price sticker, “8 pound, thanks hon!” She kissed him on the mouth.

I also remembered the day she told me about her ring. The ring was a turning point. She had talked about it for months, how they were getting it prepared, “We picked it out on the Internet, if I’m the one that’s going to be wearing it, I’m picking it. There was a special offer; it was twenty percent off... I put in some money too, and we got it insured up to 1000 pounds, so if anything happens to it or it gets stolen, at least you will have enjoyed it for, say, two years and you’re covered. I like to have things insured.”

I met her one afternoon at a bus stop near the London Eye. She wanted to cook something for us at her boyfriend’s hostel. She grinned. She was carrying a small, bright orange reusable shopping bag with a large yellow happy face printed on the front. When I approached her I saw it was filled with an assortment of ciders, rose wine and soda, on her other arm hung a Tesco bag filled with more groceries: pastas, meatballs, a few vegetables and jars of tomato sauce. She put the bags down and flung out her left hand in my face and screamed, which was quickly followed by another scream from me. “It’s beautiful, Regina!” I exclaimed. I held her hand to look at it more closely. “Are those real diamonds?” I asked. “Of course,” she said, “White gold, and real diamonds. I don’t want any fakes.” Silvery sparkles flashed as the afternoon light hit the ring on Regina’s waving hand: a slim band of white gold, studded all around with small, faceted diamonds.

Regina's efforts to make some variety of love work for her appeared mutually joined to reality and fantasy. Benjamin (1978: 75) reflects on the conscious or sometimes unconscious expectations of romantic love and lovers, what we think those experiences might hold or create for us, "In a love affair most seek an eternal homeland. Others, but very few, eternal voyaging. These latter are melancholics, for whom contact with mother earth is to be shunned. They seek the person who will keep far from them the homeland's sadness. To that person they remain faithful." Berlant has written about the importance of reappraising our understanding of intimacy and its multifaceted functions in day-to-day metropolitan life:

[...] to understand collective attachments to fundamentally stressful conventional lives, we need to think about normativity as an evolving and incoherent cluster of hegemonic promises about the present and future experience of social belonging that can be entered into in a number of ways, and that can best be tracked in terms of affective transactions that take place alongside the more instrumental ones. [Berlant 2007a: 278]

I take her suggestion as a further inquiry into how and why we are attached to ways of living that fracture our senses of welfare, and the "affective transactions" alongside more instrumental ones. By transaction, Berlant suggests an exchange, if an emotive one. If anything, for Regina, the arrangement with her boyfriend was an arrangement of anxiety. This particular affective transaction was firmly attached to an instrumental one: legality, the right to work and permission to stay in the country and so forth. Where their relationship was strained was exactly, so it appeared, at those points when the instrumental was brought out, as being the "real" reason for their relationship. But the problems of the instrumental were also sometimes, it seemed, momentarily replaced with dreams of what might be possible.

Anthropologists have had a long fascination with the subjects of gifting, elucidating what happens in such exchanges and encounters. I hesitate to say I can clarify what dynamic “help” generated for Regina; or to categorise her expressions: soliciting help in dignified terms, having nostalgia for community, or contesting self-help discourse, (though there is perhaps something further to be said about that). Our chats were regularly jolted with complaints about and exhaustion with well-meaning people in the voluntary sector. To speak of charity from a position of intense and deeply felt need, however, leads to no less illuminating conclusions. Regina elaborated on issues of seeing, particularly as something that accords recognition and human worth, and, interestingly, on the theme of what one considered to be “waste”:

You look at her – because she feel like, this person's soul is no good, look at no good and thought, but she something. And that makes her, a human being. Because when people look at you and say “Oh, she's a waste of space”, and then treat you like you're a waste of space, then your confidence go down. But when people look at you and don't feel a waste of – they feel a waste of space, but think and see that you can be somebody. If I give you this, if I help you with that, it's not like, people say, “Oh why do you need a handout?” I said, “It's not a handout.” In this life, God gave us this life to take care of each other. This is why we're *here*, to look after each other. That's why there's hospital, that's why there's mental places, that's why there's schools, because on your own, you are *rubbish*. You need to take care of each other. You need someone to take you somewhere. You can't take yourself somewhere.

[...] I believe, if people can just adopt one person somewhere, don't have to be a family member, because I believe... you know the first thing that broke my heart when I first came in this country, people *die*—for months nobody know they're dead. They're just waste. Like, elderly people. It's a disgrace. For someone to be *dead*, even for a day, for nobody not to know that person is dead. Someone should be *caring* for somebody, even if it's phone call, or a scream over the gate, “Hi, you ok!?” or a knock on the door “Hi, just checking on you!”. Simplest thing. And that makes the person think that someone loves them. People are dying in this country and nobody knows they're dead.

People are dying in this country and nobody knows they're dead. I looked in the faces of those chipped dolls with their oversized ears and eyes, their wide grins. I thought of the prospect of Regina losing the small grip she had come to have on her life. I looked at her toy and clothing and accessories collections and her. It was tempting to cast one situation, plastic animals and platform shoes, as trivial, and the other, dying in some street or overcrowded hospital in Africa, as serious. The latter was a real possibility for her, not some magazine cover story. And the former, the small faces she made a point of gazing affectionately into, lovingly wiping the dust off their noses; or the shoes she spent ten minutes deciding on and another ten lacing them up, these were real too. We live in a Barbie world, a plastic world. Regina's previous comments, about living in a place where a person could be broken up and tossed, suggested less a stripping down of humanity into biological matter, than a comical assembling of figures, not unlike her collection of treasures, which were chipped, patched up, repainted and tossed out at will – changeable, removable and disposable things that they were..

Going back to the sculptures by Marc Quinn that I mentioned at the start of the thesis, the HIV positive woman who posed for the project, Silvia Petretti, had briefly detailed on an HIV policy blog why she agreed to participate. Her remarks about challenging stereotypical representations of HIV positive persons resonate with much that Regina elaborated on, about how she wanted to be perceived, as someone healthy, normal and attractive:

When I look at the sculpture, I see a woman peacefully asleep, delicate, light and mysterious. I see my body question assumptions of what someone diseased should look like. I hope it will be a reminder to a wider audience

that people with HIV are just as human, and therefore as complex, as anybody.²⁸

At the same time, Regina significantly problematises Petretti's sentiments about the criteria for being human, how HIV is not the only factor limiting inclusion, nor is it the only source of frustration. This chapter has argued that projects of self-care and intimacy have implications for questions of who and what enables a sense of worthiness to take shape. It has shown how these movements and efforts gain traction through initiative, breakdown and fantasy. In the next chapter I take up more specifically the question and idea of "being dead" if one was still "back home". How do we elucidate and qualify seemingly reductionist justifications for being, and staying, in London?

²⁸ <http://hivpolicyspeakup.wordpress.com/art-and-visibility/>

Chapter 6

Second chances and ordinary thresholds

I learned many things. I learned to be humble. I learned many things. I learned more English, I learn many things. Respect... respectful – British people – they are respectful. The British people they know how to give. If they don't want these things, they can put it outside, anybody want – they can take. They are kind. [In] UK, if you are sick, they will take care of you, they bring down blood [blood pressure], they take you to hospital, they don't discriminate, they will fight to their last, to make sure that you live. [In] Nigeria, even though you are dying, if you don't have money, nobody will help you. Even though the person is dying, you have to pay. They [the British] do what they can, they will help you, they will fight to the end. In Nigeria, if you don't have money, even if you are dying.... The medicine there [in Nigeria] is fake. The real one they sell at the pharmacy, high price. [Excerpt from interview with Nancy]

The thought above was prompted when I asked one of my informants, Nancy, if she learned anything interesting or useful since arriving in the UK. She draws stark comparisons to Nigeria, not only in access to medication but also in how different she finds the treatment of the sick. Availability of resources and infrastructure underscore how place and location are highly sensitive issues wherein human life is literally on a threshold. But I was surprised at how Nancy's response shifted quickly to principles of kindness and being kept alive at all costs.

I can recall during one group meeting, a scenario played out, not unlike that described by Nancy. A woman from Africa had just arrived in London and found out she was HIV positive in a local clinic. She was distraught and disoriented. The facilitator asked the audience to identify the main features of her situation. One person shouted out, "She's in London!" Another client added, half smiling and shaking her head with a knowing look on her face, "If she wasn't in London she'd be

dead!” The facilitator nodded in agreement, “That’s right, she’s in London; there are the best doctors, the best hospitals here, so it’s not all bad.”

Previous chapters of this thesis have explored interpretations and pedagogies of self-care, senses of place and time, positive affect and thinking, in the context of migrancy. I have emphasised throughout the limits of biosociality and identity via shared illness, and experiences of stasis and chronic temporalities. Discourses of positive thinking and living are both optimistic and hopeful. What I would like to draw out more explicitly in this chapter is what branches of anticipation and reticence might spring from a trajectory of hope. Rather than speak of hope on its own, as something in and of itself, I consider its offshoot in the concept of a second chance, as being in the same family of expressions and sentiments, (for instance, “there’s hope” “there’s a chance”). I look at 1) how a “second chance” is constituted, what it means and how it is relevant for my informants; and 2) the different ways in which it can run its course –a second chance does not always work out the way one hopes.

I start with a few remarks on the current literature on hope and second chances and reflect on their relation to mutually stigmatising features of illness and the absence of home and rootedness. Following are ethnographic illustrations of what a second chance meant for some of my informants. They show the extent to which their experiences cannot be neatly parsed into pharmaceuticals or resolutions about citizenship documents and place of settlement, be it country, borough or housing. I problematise how threshold arguments, as being, or having resided, on the border of life and death, could be explored for thinking through the broader

permutations and conflicts embedded in “ordinary thresholds”, and in living up to the expectations and hopes, moral and social, of others.

By “ordinary thresholds” I mean limitations that test not whether one lives or dies, but what is considered worth pursuing, tolerating and living. Specifically, my examples and supporting case studies look at questions of estrangement, friendship and gifts. Estrangement has been suggested in this thesis as a feature of my informants’ lives, I want to highlight further here the ways individuals felt cut off and cut away from current and past kin and place relations. Friendship was more elusive than love, the latter of which came up consistently in group therapy in the subject of relationships, romance and the difficulties of finding a partner. Support groups built around peer support and friendships had a distinctly pragmatic sense about them. Here, I look particularly at the idea of friendship among, and with, strangers. The idea of gifts is another theme that speaks to issues of how one does, and is expected to live out, their second chance. Antiretroviral therapy and health care provision would appear to be the greatest gifts of all. Nonetheless, this does not exclude how informants, and researchers alike, might reflect on such things, their complications and consequences, in terms of gifts. Reflections on the giving of biological material have brought up similar such questions about the difficulties of “renewing” a body (Sharp 2006; Waldby and Mitchell 2006). I ask what might be gleaned from exploring narratives of a “new life” through the prism of the gift.

Hope for the body

The theme of hope has been a mainstay in medical anthropology, both in terms of political projects that speak to the political and economic functions of hope,

and the everyday, individual and collective experiences and interpretations of hope (Del Vecchio Good et al. 1990). Considerable scholarly and activist activity has built around the presence and provision of medication as a symbol and act of hope (Robins 2004) for the HIV positive body. The political geography of ARTs has been equally resonant. A third sector umbrella organization representing African communities in the UK launched a campaign in 2008 demanding the Home Office delay the deportation of persons with HIV from the UK, “[...] until antiretroviral treatment becomes more widely available and accessible” (African HIV Policy Network 2009). The policy officer previously involved with the campaign reiterated to me that they were not denying the right of governments to remove people from their borders, but only that it had to be done with the human consequences in mind. And more importantly, it had to be done in as informed a manner as possible – she stressed the need for studies outlining exactly what ARTs were available in individual African countries and how people would access them. However, she also emphasised the organisation’s efforts to increase awareness of the scope of pressures faced by HIV positive migrants living in the country, and the sense of helplessness (and perhaps hopelessness as well) that can be so pervasive:

Right now, what we are working on, we have broadened from HIV to look at other health conditions, including TB, mental health, stroke, cancer, and diabetes. And *a lot* of the causes of most of these is just sense of helplessness, to say ‘what’s the point?’ Mental health is becoming very high, people are confused, they *can’t get a job*, just because, they’ve been here illegally. Now when you think about, it doesn’t take a genius to say: if you let people work, they will contribute more to the economy. It’s very common sense. So... I know, it [immigration] is a very controversial issue, but it needs to be looked at very, very carefully, and seriously, because it’s impacting on people’s lives to be honest. [Excerpt from interview]

She highlights the trap of “illegality” that many people find themselves in. The inability to work and be productive members of society in effect cancels out one of the primary markers of citizenship and legitimacy. It is not surprising that these vulnerabilities meant informants relied much more on what people and institutions might be able to do for them, than what they could necessarily do for themselves. Sources of hope ranged from medicine, documents and state permission, to more informal things like making the right associations (friends, partners, support workers, middle authorities); or gathering bits of money for phone credit and transport. Commonplace matters that were not particularly dramatic but could make a difference in what it meant to live daily. Is hope still hope if it is ordinary, if it no longer compels and revitalises, but becomes repetitive? What is the nature of hope, how is it expressed, and what is it about that expression or experience that characterises it as ordinary? And following from that, what are the implications for how we think about hope and second chances?

Migration and pharmaceuticals converge here, but quite accidentally. For most if not all of my informants, coming to Britain had little to do with HIV. They came with aims not dissimilar to other migrants moving around the world: to work and earn money, study, and/or leave socially, economically or personally difficult situations behind. There was a technocratic version of frustrations around migrant settlement that I encountered when speaking with specialist settlement agencies, namely, the new logistical hurdles for entry into the benefits system, housing, and employment, after years of being cut off. Likewise, the second chance offered by medication was overshadowed by its own challenges of physical and psychological adjustment and side effects.

Whyte (2013) has suggested approaching HIV in terms of generation, with different experiences of medication and the opportunities afforded by being an HIV patient, and increasingly, a client. Speaking in the context of Uganda, which in the mid-1990s saw a spike in international support for the HIV epidemic and made the country a pioneer of HIV engagement, Whyte speaks of the “decentreing of AIDS”. She raises the theme of second chances specifically in light of the “reprieve given by antiretroviral therapy”, and created a “generation of survivors”. Second chances as she put it, involve “reprieve, contingency, conversion and reflection”. Quoting Das, it can be about pursuing routine, ordinary matters, and continuing the same life one had before.

She points out that with ART therapy comes a kind of citizenship and a kind of “clientship”, exemplified in instruction, pledges, programs, paperwork and surveillance. A “conversion to clientship” begins to take place as prerequisite, that is, you need to be a client if you want that second chance. Whyte also discusses the “chanciness” of second chances: life is insecure, a “gamble”, drawing on the Ugandan term for getting by. Surviving, she notes, is a creative idiom. Further, there is a particular amount of reflection, “secondness” and “second thoughts”, in rethinking one’s body, children and family (Irving 2005).

Whyte’s points are helpful for thinking through the nuances of statements such as, “If I was still back home I’d be dead...” What are we to make them? Can we reflect further on how it in some ways appears to contradict stories of hardship and trial? Can we tease out what they are suggestive of and what they write over, and find alternative ways for thinking about what it means to have hope and to be granted some?

Such utterances of life and death cannot be reduced to an argument of bare, biological life (Agamben 1995). They are in some ways sustained by a certain temporality: crisis/emergency time. But once time has moved on, there is also occasion for rethinking the statement. The rationale and experience of “bare life” in light of a second chance is multifaceted. As this thesis is interested in extended interruptions and the meantime: the drifts and ambivalences between the life you once led, the one you do live, the one you hope to live..., hope is manifest in unexpected ways, and may act as an anchor for motivation but not the fuel for carrying on.

Might we entertain questions about what lies beyond hope? Either in the sense that it is no longer necessary when crisis or emergency time has passed, or because it is exhausting and there are less tiring options? And if there are alternatives to an attitude of living well, wherein some measure of respite rests in other idioms?

“You think you can do anything, but you can’t”

The following is based on field notes recapping a phone call with one informant, Sandra, a woman in her late thirties from Uganda who had received her leave to remain about four years ago. I note our exchange here in part because it speaks plainly to the ambivalence of living with a body prone less to crisis than extended weakness, and the compromise this entails:

I just got off the phone with Sandra. She always seems to be laughing, even when she’s not well. The phone rang and rang and I was about to hang up when she picked up. Our conversation went something like this:

S: I’m on the street, I didn’t hear the phone.

D: I thought you were sleeping.

S: No, no, no, I just didn't hear the phone. I'm doing some shopping at Seven Sisters, it's about 45 minute bus ride from my house.

D: That's a long journey!

S: Yes, but, well, I have much time, I like to look around at the shops, then when I go home, I am tired.

D: How are you? Have you seen Dr. J? Have you been to the Jobcentre?

S: I went I went. Dr. J put me on 10 mg steroids. I will just do that. I will be strong. At the Jobcentre, I saw the lady, I told her the course I want to do. She said, I could be wasting my time – I can't be a mid wife. She said to have my doctor send her a report about my condition, and then she will assess me more.

[Sandra paused]

S: You think you can do anything, but you can't.

D: Did you tell her about the English course, and the medical assistant job?

S: Yes, I think I could do that – it's not too heavy for me. But it's the cost... she doesn't have the funds. I can start the course on my own, but the medical assistant course is very expensive. I don't blame her for saying that [that I'm wasting my time]. It is so stressful, Daisy, but it's not like before when I didn't have my leave to stay, it's not like before when we didn't know anything about this condition.

D: Are you going to any groups around west London?

S: No, I go to my borough. It's just, I have to take painkillers and after 8 hours the painkillers have stopped. I don't want to always say to people, "I'm not well, I'm not well", the more you say it, the more harder it is. I only talk to Dr. J about it. I will act like a normal person. [Extract from field notes]

Sandra consoled herself with the fact that she was much more informed about her HIV than ever before, as well as with the assurance of having her permission to stay in the UK formalised. Despite how hard it is, she resolves to "act like a normal person". Following this call, we did not speak or meet again for a number of weeks. I was able eventually to reach her via text and she messaged me her email address and latest mobile number. I sent her an email asking how she was faring, to which she replied the following:

I have been ok and the situation is still the same,i have seen my Dr. but there is no alternative i have to be on steroid but he has added on hydrochloroquine and he said this will help with the side effects of the steroids because i still need them because my Immunual system is over reacting and it's not TB.

You know what i have left every thing to him and God will guide him to find me a solution after all i have come from far, he saved me it was like i came from the dead, i trust him. [Spelling and spacing in original]

Sandra's remarks about being saved by God and the return to health showed the entwining of physical and spiritual experiences and objects. One might also find a trace of cross over between the figures of God and her doctor. When she says she trusts "him", she affirms her faith in her doctor, but also that he will be sufficiently aided and facilitated in his work and care of her. I took these last lines as an acknowledgement of a key event in Sandra's life, and read them as examples of a certain hopeful orientation engendered by that fortunate encounter. It was an event set firmly in the past and which could now be conjured in the present as something that might once again intervene to good effect. HIV medication's "Lazarus effect" has been a significant analogy in professional and scholarly discussions about how bodily transformation for persons with HIV can be deeply awe-inspiring (Rasmussena and Richeya 2012). The notion of coming back from the dead is a powerful one, speaking to the role of the extraordinary, and extraordinary situations, in marking particular passages through time. This, though, is positioned in the past, a previous testimony, rather than an existing achievement. She simply states that her situation at the moment is "the same".

Sandra's observation "You think you can do anything, but you can't," pointed to the weaknesses that were the flip side of her strengths. Her thoughts echoed that of Nancy's, who I quoted at the start of this chapter. Nancy was in a radically different social position, as she was not being supported with benefits and private council accommodation as Sandra was, but she also reflected on the precariousness of her body. She was relatively newly diagnosed but she emphasised

her problems with high blood pressure, reiterating how the hospital has given her treatment for it. I asked her what she thought made her blood pressure “high”:

N: Maybe it's the thinking...

D: What do you think about the most?

N: I think, no house, no job, and the sickness. Everything. I have to do many voluntary work so that I will leave the house [laughs]. I do many voluntary work, I do voluntary work. Cleaning, like in Salvation Army, cleaning, I have to wash the toilet, clean. At St. Mary church, we used to help wash plate, cleaning job. There's a church, I do cleaning, the Salvation Army, I do cleaning. There's nothing I can do. When I'm busy, I don't too much think about it. Thinking too much is no good because it makes blood pressure go up.

Nancy's efforts to preoccupy herself so she does not have to “think too much” were tied to what she could and could not do. She did not have her papers and was not able work, but she looked for ways to keep moving. Nancy attended HIV support meetings as part of this work. She also maintained a careful distance to people whose circumstances were similar to hers:

It's just “hi, hi, hi” [in] the other group. There will be class, this one, so it was very nice, there will be music, so teaching people how to dance, so they will be beating the music. I don't have friends, I used to come and have coffee, like, with Janet, then it's “hi, hi, hi, how are you?” Not friendship. I don't know, friends I don't like too much, the “talk, talk, talk” [laughs]. It's not good. I don't have time, because I have to go voluntary work, I have church, so I don't even have time, friends coming sitting in the house, talking. I like to walk walk walk, [rather] than talk, sit down, talk talk. [laughs] [In] London, everybody have to struggle! If somebody get his paper, collecting benefit, you don't have anything, she will sit with you, talking, talking, waste your time, and end of the year, she collect her money, and you are empty.

The “walking” (over the “talking”) Nancy speaks of is a critical term and act through which her body has capability and control. The irony of support group work, much of which is constituted through words, speech, language – talking, essentially – is clear. Being acquainted with other peers and how they are living brought less hope and optimism than renewed frustration with one's own limitations

and circumstances. The body that keeps walking and moving, despite all that it cannot do, is the body that maintains momentum and sanity.

Maintaining distance

Eugenia had an immigration application in progress but, like Nancy, was not accessing any funds or benefits. She did, though, have a travel pass for unlimited transportation and a weekly grocery voucher. Also, unlike others in her groups, she did not attend church regularly nor was she particularly enthused by Christian theology and community. She talked about how her neighbour down the street was Christian and had tried a number of times to convince her to join, regularly slipping leaflets under her door. Eugenia said she was a friendly lady but that she simply “didn’t feel motivation to go to church” and felt “pulled back by this immigration thing”.

She and I met one afternoon for a meal at her “flat”, a room in a house shared with six other people. Her room was on the third floor with the shared kitchen on the ground floor. I asked her if she lived well with her other flatmates. She said she kept her distance and no longer bothered with putting up notes and messages about tidying up. She also stuck to small talk, “If its gets too comfortable... you will know too much about one another... you’ll lose that respect and consideration.” She told me she had risen early that day to prepare our lunch, before everyone else started using the kitchen. She had prepared stewed beef with onion, rice and salad. She plated up for me first and handed me the food on a tray, suggesting I go up to her room first.

I ate at her desk and she sat on her small sofa with her tray on the coffee table. She dropped her fork on the floor and excused herself while she went to wash it. When she came back and sat down, it fell again to the floor. She laughed, shook her head, said she was not sure what was the matter with her today, and excused herself again to wash it with soap and water. When she got back we settled into our meal and chatted about a recent story in the news about a young couple whose honeymoon was destroyed when the husband was killed by a shark. Eugenia remarked how horrible it must have been to have one's funeral in the same church where one was married only weeks ago. She shook her head, saddened by how careless the couple had been, "It shows you how people can be so casual about life."

Eugenia might have appeared to have a large network of relations and kin, professional and social. Her son was a rising entrepreneur who travelled often outside of Africa. Her sister and her family lived in the north of England. Out of all her family, only her son knew of her HIV status, she said she wanted him to know and learn from her experience, but she did not see the point of disclosing beyond that. She had a brother living in Nigeria, whose daughter had passed through London recently to visit her boyfriend, but she did not stop to see Eugenia. Eugenia was unimpressed, "She said she was too busy! Too busy! Doesn't have time even to see her only aunt here that she hasn't seen for 11 years". Eugenia said she was always the one to call her brother in Nigeria. She mentioned to him how upset she had been with her niece but he defended his daughter and did not apologise. Eugenia has not spoken to him for the past year.

"I don't make friends easily," she said when we got on the subject of what it is like spending time with other people that have HIV. At one group she used to go

to, she spoke of how the coordinator had tried to start an HIV positive singles group. “You’d think everyone would be happy to meet someone who was in the same situation as them, so you don’t have the disclosure issue to worry about, but no, it’s the opposite. People went for easy sex rather than relationships, one week this person with that person, next week another, back and forth.”

Eugenia herself has a few friends in the groups, but they were “friends outside”, she said, and she mostly left a space between the groups and her day-to-day life, “Well, life is... especially at the moment, it's not very easy... especially when you don't have immigration status like me. It's not easy, but um... I suppose it could be worse for me, it's ok it's ok, 'cause... emm, I mean there are these groups which support us, in terms of emotionally, it's ok.”

She told me she had the symptoms of HIV back home but never received a formal diagnosis. “If I had known, I don’t think I would have had the motivation to come here,” she says. I asked her about whether she would “go back” given the chance?, Eugenia replied, “Coming to London saved my life. I got my TB and HIV diagnosis after arriving. I’d be digging my own grave if I went back. There’s no Mark over there”. Mark was a support worker who helped with her weekly shopping funds.

She paused. Then continued, “The UK government, need[s] a war over there to have reason [for me] to stay here, there is no war in Zambia, but there’s poverty.”

In an earlier interview she clarified that she had initially applied to stay in the UK under a different category, but had been ill informed about the process. As such her first application as a student was rejected, and later when she applied to extend her travel visa, she was rejected again as she had already overstayed:

D: I guess you didn't apply as an asylum seeker, that's obviously a different category...

E: No I didn't, that's another category. I didn't apply as an asylum seek – because, politically, my country is quite stable.

D: But it doesn't mean there's the right treatment...

E: No, Daisy, no, things like medication, people still die there of HIV as we are talking now. Because, I don't know how, I don't know, whether they say there's medication but people are still dying. Whether they say it's only for people with money I don't know...

D: If you have money, you're taken care of...

E: Yes, yes, because they say money speaks

D: They say that here too.

E: But here at least, HIV in this country has been reduced drastically

D: So now your solicitor is trying to make an argument based on your medical condition... that the medication you're on is unavailable in Zambia?

E: Well, I listen to my solicitor, the Home Office – the solicitors were asking about why they've not responded. So they [the Home Office] asked for a medical report. And I went to see my consultant in January to give me a medical report. Until this medical report—my consultant says, because they want her to explain, if supposed this lady was removed and taken to her country, is she going to have the same sort of facilities as she's got here? Medication, things like that – so my consultant mentioned, even if she went *there*, even if there's medication, it's not the same like the ones she's getting *here*. I don't know where that medication comes from... but...

D: But it's not the same as what you're on now...

E: No it's not the same. It's different. How different I don't know, it is the consultant who says that. It wouldn't help me as much... Then she also put that my life expectancy, it—it—eh, it's been ehmmm it's been eh... increased because of the care that she's getting here. Whereas if she went [back], well, maybe she could stay one year, she says, or, well... less than a year. That's what she say.

As Eugenia recapped these legal and administrative proceedings and conversations that were summarised to her, I could see how the process was a distant and alien one, even though they were about her and her life and body.

E: Now it's been 11 years on, I'm 12 years in July, 1st of July, 12 years. If they wanted to remove me – because this is what the judges say, they say, if, directives are given to remove her, she will then have, she will then have... she can appeal to... to the human rights whatever. If they remove, or if directives are issued, she could... they were empowering me to say, if they ask, if they have to remove you, you can do this. Because they have to write a letter, like, putting everything, what was said during the session at the courts, but in conclusion, they said if directives are issued to remove this lady, she has a right to appeal. How do you – how do you remove somebody

like that? Because it's already like I know that you can't remove me. So umm so me I'm not going nowhere [laughs out loud] Definitely, you see I'm not going to Africa to die. Going there, I can't leave here.

D: Is London home?

E: If I... I think it would be there and here. It will be there and here. And there's been a lot of change [in Zambia]. 12 years is a long time. You lose friends, family, people change, they migrate, and some have passed away, with the HIV...

D: The community you left behind has changed.

E: Exactly, who is this one, who is this one? I don't know this one... things like that... sometimes, the people have grown up, they mean a lot to us, because they know us better than any other person, because if you know somebody in your 20s or 30s, they know you. Sometimes, I don't know, maybe its just me, it's not easy to make genuine friends when you are of my age. Genuine friends.

Being positioned within two localities, Eugenia's citizenship was spread out in an uncomfortable way. The home she once knew was no more, and the home and place where she is having a second life is also not something she can count on to provide her with a full sense of belonging. Her companions are distant others who are wrapped up in their own individual negotiations and insecurities:

E: You can bond when you are young. 19, 20, 20s, 30s, you know, you bond with people. They know you. Sometimes you can – people would like to be your friend, who you are, if you're anything at all, which they can benefit from. And you know, it's difficult to make genuine friends. Friends are there. But who cares? What is your definition of friend? Genuine, I mean genuine friends. For me, I'm talking from experience, because as I've grown older it's very difficult to make genuine friends. When I miss my friends from when I was 16, 17, because I've lived in Zambia, and went to Zimbabwe, these are the two countries where I have genuine friends.

D: Do you have any genuine friends in London?

E: This is what I'm saying. No. Completely different. You know, they don't know you, you know? They're... for lack of better definition, they're just people you know. Not friends. Because friends, you go beyond, these are people who are there for you when you are in problems. Yeah, yeah. But here, you know, you find, you know, somebody, they will be talking to you only for two years, or one year, oh "I just want to say hi", but you don't see each other.

D: Has the HIV helped you make friends with other HIV positive people in the groups?

E: No it hasn't. Well, I've got acquaintances, but it doesn't mean to say those acquaintances are my friends. I've got acquaintances in the group...

sometimes they're looking for friends, but you can't find them. Yeah, yeah, and um, well a friend is easier lost than found, is that saying. So, yes, in these groups there are acquaintances, but they're just acquaintances.

D: So when you come here, the people you meet here...

E: They're just people I know. I wouldn't really call them my friends to be honest.

D: Just because you all have HIV...

E: ... we're just bound together by the condition? But uh, they're not really friends... because you can see from the way they behave. Yeah, they're not really friends. Well, you take people the way they take you. If you're not their priority why should you take somebody, why should you prioritise them? Yes, we all have different personalities, we all have different personalities, and what makes people keep as friends is because they – they have some things in common. Yeah, maybe some have got friends, I can't speak for them, I'm speaking for myself.

D: The sickness is not a strong common thing...

E: No no no, no – sometimes, you *feel* that because you're all in the same situation, people can be friends, but – everyone has got their own type of personalities they would like to be friends with, or, I don't know, I don't know, it's, but, uhh, it doesn't make us – this condition does not make it easy to befriend a person who's got the same disease.

Several informants said repeatedly how much people in African communities loved to talk about one another. The boundaries people drew between one another was as important, if not more so, as establishing close attachments or trying to have a second “family” in the spirit of managing one’s condition in good faith.

I asked Eugenia if she thinks about her things, the possessions she left behind. “It’s been 12 years, Daisy. I sold most of [my] stuff, the clothes I gave to a cousin. I came to London just with a small carry-on – that’s a souvenir now!” She laughs. When she found out she was sick with HIV, she thought the end was near and set up a joint bank account with her children. She also asked them to do something about her property. Her son said its structure was rotting and suggested it should be demolished so the land could be put to better use. She shook her head at the memory of how she reacted, “I didn’t think,” she said, “I didn’t think I would be well, so I closed everything down.”

Eugenia did not dwell on what she had left behind in her home country though, and told me how she would like to start a small business there if she had the chance to return. She also remarked that if she did receive her leave to remain in the UK, she could make changes the next day, “It doesn’t mean you need another 3 or 5 years to adjust!” The subject of people with papers who were reluctant to work came up again. “If you want more money, go out and earn it!” Eugenia shouted as she walked to the small fridge by her wardrobe to get us more cranberry juice, “Just because you have sickness, it doesn’t change you, all of your personality.”

Eugenia was deliberate in her choices about keeping boundaries with people: those she had to share her domestic space with, her HIV positive peers, and different members of her family. And she appeared to have drawn lines as well between the HIV and herself, pointing out that it was not reason enough for changing how you might go about doing things if you had not fallen sick. I could recall another time when she reflected on how she felt when she was still adjusting to the idea of being HIV positive, saying how she felt she had “lost her beauty”. But now things were different, she said, and she felt good, good enough to wear shoes with heels for instance. Her comments reflected the hard won achievements of feeling normal again. However, the carefully guarded the stability she had managed to establish thus far, and the new lease on life she had been given, entirely as a consequence of unforeseen events, was sometimes quite separate from her social and personal relationships, which demanded a different kind of care.

“You can live”

Mary was one of the first people I met in the groups who offered to speak with me. She suggested meeting at her flat, which would save her the trip across town to the group’s office. I remember making a roundabout journey after getting off the train that day, and coming up to a small house with faded and chipped paint and a creaking front entrance. She buzzed me in and told me to go up two flights of stairs; her flat was the first one on the left.

When I stepped in I saw a blue woven mat on the floor, a red coat hanging on the wall closest to the door, suitcases and boxes could be seen balancing precariously next to the bed. A small television sat in one corner of the “studio”, essentially a single room with a kitchenette, which was two steps from the bed, consisting of a small cooker and mini fridge. Two bottles of washing up liquid stood by the sink. A very large microwave rested unevenly, half of it sitting on the cooker the other half on the counter. I asked her where she normally ate her meals, she pointed to the small table next to the bed in front of the television, “I usually sit here on the bed or on the floor”.

I handed Mary a plastic bag with some yogurt cups and grapes I had picked up on the way. She opened the bag, “Ohhhh! Thank you!” I laughed and reminded her of the importance of “good nutrition”, drawing out the syllables as she did when we met at a healthy eating workshop. She laughed as well, nodding in agreement. She put them away in the fridge, as she opened the door I saw there were plastic containers of food neatly stacked on the shelves. Mary then sat down on the edge of the bed and I sat on a small stool next to it.

I asked her if the heating was ok in the flat. “The heating is good in the studio,” she assured me, looking around, “Even though there are rats and they keep me up sometimes at night”. She said she had been offered a larger flat in north London but decided to stay put in order to be close to the networks she had built up over the years: her church, the hospital that she volunteers with, and her hospital near Whitechapel.

Since I was asking about her movements and whereabouts, she asked me about mine: where I was from, the places I have traveled to, how long I have stayed in each city, and where I might be going next. She said she knew another Daisy, a Canadian missionary, from when she was in Uganda. She had come to work at the local missionary hospital, and started a local textiles project in Mary’s town. They began making patchwork and bags, “While we worked on the patchwork everyone went around the circle and talked about what they planned to do”. Mary said at the time her plan was to sell bags and open a small shop.

She had children in Uganda, but did not speak further about their current whereabouts. She also said little of her husband, only that he was not home often. She left for the UK a few years after he died. She shook her head, saying it was fifteen years ago; that as soon as gets her papers, she would like to travel. But not to Uganda, she said she wanted to go to Canada and see the lady who began the patchwork project. We laughed at the coincidence of first names and nationality.

As Mary explained her circumstances in the course of our conversation about how she found life in the UK, and the assurances she had been given by doctors and lawyers, she often repeated, as a kind of summary, “You can live”. She clasped her hands together, “When I made my application, she [my solicitor] said, ‘Don’t mind –

keep doing what you're doing, be patient,' she said, 'After 10 years, you're definitely given....' This story – I don't know... It's been 7 years, almost, almost, almost 10 years, so... we keep working". Her narration spoke to her own experiences of making sense of being able to live with HIV, as well as how it was the kind of gift that made demands on a person, on their own willingness to participate, to persist. She continued:

It was very bad for me, because, my husband had died, and, yes, the relatives know, so – when I got someone to say they can bring me, I came. It was very bad, mmm, uhh. But now, the doctors are *very* good to us, the solicitor is good, good, so everything you can see that you can – you can live. [...]

Even that's one of the reasons the solicitor say, "If she's sent back to her country, definitely she will die, there is no way she would get treatment". So that's one of the reasons the solicitor said she has to stay, "she has good treatment". Because how I started, when I had come in 2002, there is a great difference. [...] I had chest pain, and uh, so I was saying, maybe.... with my back.... I had TB of the bones... there were different things.

Asking participants when, where or how they became sick often conjured a variety of ambiguities. Mary said once or twice that she knew she had HIV back in Uganda, even though she was not sure what her husband died of, and was not diagnosed till she arrived in London. But she also talked about having grown ill previously with assorted pains and conditions. It was difficult to identify the timeline of what condition cropped up when. Someone in Uganda had helped arrange her travel to the UK, but the details of these beginnings were also something of a blur:

That time, we just pass through the barriers and we came, I think this one, is like, he has a way... [the person who helped her come through], I never saw him again, he disappeared, I don't know. It was just me [at] that time. Because we had crossed the barrier – there was no police.

I've never been here; I've never been here. When I arrived, before I came to this country, there is a lady whom I knew, she had given me.... she came and

meet me... she's in.... what is that place called... Lewisham.... It was a few things I brought... because I was not feeling ok, I was very weak, so she said you better go to a hospital, and check what you are suffering from. They checked, they give me some tube.... then... there was a good counsellor, she said you know you are HIV positive, there is a possibility of living, there is medication, you will be ok [...] I was surprised but nothing I could do, it had happened. He [the doctor] was good, he was just encouraging me that people could live with that sickness, that if you get the right treatment, if you eat the right food, you can live.

Mary was well apprised with the guidance given about the possibilities of a normal life expectancy with HIV. She could not remember how or where she was given her solicitor, but said one of the HIV support group charities helped her source one. She repeated that her solicitor has made the case that if she is sent back to Africa she will die. She was of course worried about her application. She spoke most profusely though about charity and forms of “gifting” that she has seen in Africa but also in London, and the gifting she herself does in the form of voluntary work:

You know, in Africa, lots of the people are corrupt, because the white people, the Europeans, sent donations – help – to Africa. But people, they all want [to] put it in their pockets. So now, the difference between this country and Africa, there is not so much difference between rich and poor, *here*. But in Africa, the rich are *very* rich and the poor are *very* poor. Corruption is corruption. Even the charity shops, the Europeans try to help, but it's because – the wrong hands... the money doesn't go to [the] right people. I think it's difficult for them to go and monitor. Even if they said they are going to check the books, they do forgeries.... they are not doing it, they convince them...

There is perhaps little that is surprising in what Mary says here about the major differences of poverty, and gaps between classes, in her country of origin and the UK. But in her remarks there is also a commentary about how the “help” that is given to Africa becomes inherently troubled and unhelpful because of intersecting channels of self-serving activity, which stop those gifts from going where they

should. I found it interesting that one of the first things Mary said to me was her experience with the missionary she had met and the assistance she gave her. She also told me about the minister at her local church in London who had helped her move her furniture and belongings into the flat she was staying in now. These references to help and good deeds did not stray far from what soon followed, which were her thoughts on the support groups she was directed to by the counsellor who had given her the HIV test results:

She is the one who give me the different addresses, organisations. The support groups are also helping us so much... you talk to people, you share, different ideas, it's good. I go. Most of the groups they meet once a month, they phone us if there's a group.... you talk freely.... and when we are talking we know that everything is confidential. So now, in the groups, whatever we talk, it has to stay in this room, we don't need to go outside and talk to people about the things we talk about. You know in the groups, they organise, people talk about different topics, nutrition, immigration...

Being able to live was about meeting others who were also able to live, although often, this was occasion for seeing just how varied this experience could be. Mary's reflections were peppered with people she had met whose health was radically different from her own. One of the highlights of her routine in London was her weekly volunteering with a charity that focused specifically on rehabilitating individuals suffering from severe physical disabilities and impairments as a consequence of HIV. She told me about one patient she had met at this centre who had shown her a photo of herself from several years ago, which she had kept:

... and when you go, it would – I have to thank God, some are.... [shakes head]. Let me show you.... [She takes a photo out from a large envelope on top of a shopping bag full of clothes] I remember, when I took her home, she [the patient] showed me this photography, she was crippled, now this is the same person, I thought it was 5 different women. When I saw her photograph, she asked me, "Why are you crying?! Because I am ugly?" I said, "No no! Because you are so crippled!!" I met her in the day care, for grown ups, clients who are HIV positive.

This patient had been what she called a “life-ist”, someone who, from what she described, was constantly socialising and testing her limits:

It [the charity] is like a rehabilitation centre or something, because it is like training them, so when they are able to stand on their own, they can go back to their community, and be on their own. But some of them still cannot. But many of them improve. But you know, now like this one... she... she was drinking, drinking a lot, alcohol, she was a 'life-ist'. You could see she was a life-ist from the beginning. She likes the life, parties, and go out. So.... when you are – are – you have this sickness, me I think, whatever the doctor tells you, you have to follow it. If they say reduce taking – your drinking, alcohol. You follow it.

They took this lady to outside London... another rehabilitation centre or what... to try make her reduce her drinking, and she was there for 3 months. If they had been in Africa, they would have left her to die, why should they care about someone who is not caring about herself? But when she came back still she was doing the same. She drink... no change. In the end she had no appetite. She would... she could not eat at all. Then she died.

Mary stated clearly here the fragile thread medication provides to living again, especially if the related responsibilities of looking after one’s health are not respected. She also spoke plainly about the implications of location for this patient, that such a situation in Africa would have meant ceasing of all care. The emphasis on self-love and motivation that many of the support groups encouraged was not necessarily what Mary was pointing to, nor was she simply being a disciplined patient when she stressed the importance of following the HIV consultant’s recommendation. Rather, I think, it was a recognition of what one could do to and for one’s self, for better and for worse. Volunteering (along with church and support groups) was one of the activities Mary could engage in that did not exacerbate her physical health or conflict with her immigration status. She also took great pleasure in the routine:

When they come in the morning, let me tell you what I do, I come at 10, we take them to the gym, we have a disabled, one, completely disabled, she's

young girl, young, yes, from the medication, so many problems, I'm telling you. I take them to the gym, most of them need to be assisted, like the blind one, you need to be with them, we take them to the gym, there is physiotherapy. [Then] at 12 we take them to the chapel for prayers, everyone every client from different backgrounds, we have a Catholic sister, we have Anglican one, so everyone, every person, we sing, we pray. I think this girl was just brought in, just newly diagnosed, so she was all in tears, so we were hugging her, telling her Jesus loves you, God loves you, we telling her, "Next week don't come crying like this, all these [people here] came when they were shaken up but now you see they are *strong*!" So.... then we go for lunch, we have lunch, there is a cook who cooks for us, they serve us, we clear their plates, then in the afternoon at 1:30, we put them in two groups, talking groups in day care; then others, we go with the sisters, we can be spiritual. She takes us out – she told us in two weeks time we can go near the seaside, have a trip, she drives the hospital van and she takes us out... So... my Thursday I like it very much. I've done it for 5 years, but I like it very much. I always say, [when] Thursday comes, I thank God for that.

We spoke about what she found difficult about living in London. She shook her head, gave a small smile, "To me, it is boring! Because in Africa, I'm used to being with the people, to eating with the people! Being in a house alone, eating food alone, is like as if you were a thief!" I asked her if she remembered what she had said to me at one of the group meetings, about how loneliness can kill people. She nodded, "I cannot stay in, I cannot die of loneliness [laughs] God has given me legs to go out! I have to go out and see people! And talk to people! And talk to people. If I stay home there's nothing [to do] but sleep and become like a fool!" She added, "All these people you meet, church or groups, it is a real family."

We were quiet for a moment and I looked around again at her studio. I ask her what the biggest pressure was at the moment. Mary nodded, touched her back as she spoke, "I know it's the house, because I have to bend, and I... I knew the problem with the back, but I never had it so painful like how it is. Because when I came to this room I thought I would be here for a very short time but now it's been over 5 years... bending and doing all this, it's a problem. But... there's nothing I can do."

I asked her whether life in London was for the long-term. She looked down at her slippered feet and up again, “Yes, it's – long term here, because I don't think that I could.... even if...[pauses, sighs] I've been in this country for a long time, so even if I get papers and I go back to Uganda, what... [sighs] I don't think that I could do anything there now.” “Too much has changed?” I volunteered. “Too much has changed” she nodded. “Are you managing?” I asked. She replied:

M: Yes, I know, because, now, like, now I have a lot of the pains in the body, and so I do... exercise, even if I'm not at my volunteering, I do exercises, I do. Because at the volunteering, the clients, we teach them to do the warm-ups, the exercise which they can do in their house. So, when I'm alone I do them like... [Starts demonstrating, jumps up and down]. I try to... [Laughs].

D: You feel pain everywhere?

M: Hmmm, yes, pain, the back is also... also the legs. I complained to the doctors, my consultant, then my doctor referred me to the consultant. She checked me about a month ago, she was asking me to hold her hand like this... because I... have a problem with this finger. It started in 2008, and uh, it was as if it has.... got, like, an electric shock or something, so when I sleep, it wakes me up, I wake up and I find this whole arm painful. So I have to stretch, so when this finger started painning me like that, the doctors checked, put a lot of things in my head, and checked and they checked everywhere, they said the tests were negative. They said that maybe when I got TB of the bones... it, now has been affected.... so I just left it like that. Now when I continued complaining, the doctors are checking, they say that I'm ok, but I'm feeling the pain. So I don't know. I feel it, I feel it... the pain is in the bone. But again the doctor, the consultant said from my report, I've been complaining about these things for a long time... [Chuckles]. So what I was going to say, at my age, I don't think that I can start work and do something.

Mary's thoughts about sustaining herself over the years drew together a variety of thresholds, bodily, emotive and temporal. She started off with the time she has spent in her current accommodation, how its size and cramped corners have weighed on her body, which have literally had to adjust to its contours, with the twisting and bending of her back, how she had not expected to live in the studio for as long as she has. The expectations about time were mirrored on a larger scale in relation to her application for permission to stay in the country. The time that has

passed since has drawn a large and deep gap between her and her country of origin, as well as creating a gap within her own life in London, a gap filled with becoming an HIV patient, support group client, legal applicant, church member, and charity volunteer.

Amid these different associations and relations she has developed she has been given assurances and approximations about what kind of timescale she can expect for her situation: with proper management of her condition she can have a normal life expectancy, it was a lengthening of time meant to be celebrated, and yet the years were marching on as her papers awaited approval. “Normal life expectancy” was something of a distant ideal and often what seemed more resonant were the expectations made of Mary, similar to other informants, which was to be patient, to take the medication, and to follow the professional guidance they were given.

Near the end of our interview she said to me, reiterating, “[...] because if I have to go back to my country, I will... I will die. So I have to be here. I'm happy that I'm here. That I'm here, I'm alive.” What I hope to have shown is that she clearly articulated herself as living proof of the link between being alive and being in the UK, but she also showed the different conversations, experiences and fragilities embedded within the “I’m here”.

This chapter has taken up the question of the unexpected tensions and ambiguities surrounding second chances. In particular, it has argued for the significance of not only verges of life and death wherein life is literally counted in terms of biological survival, but also the multitude of “ordinary thresholds” that

challenge what is considered worth pursuing, tolerating and living. My illustrations and cases have looked at the themes of estrangement and loneliness in mundane spaces and situations, and equally, at how sensibilities of uncertainty intersect with hesitations about the body, and mind, and what it can tolerate, be it unusual lumps around the throat, back pain or low mood and motivation.

Scholars writing about the donating of organs and biological matter have pointed to the conflicted nature of the so-called “gift of life”. Be it in the form of a new heart or blood, such gifts come freighted with debates and ambivalence about the responsibilities attached to giving and receiving. What do we accept when we accept something that used to belong to someone else, someone else’s body? Put slightly differently, what do we accept when we accept an agreement to be “well” again? Anthropologists have discussed the numerous ghost stories that accompany the transplanting of organs, the memories embedded in body parts and cells, the inadvertent intermeshing of a life that has passed and one that (now) has a chance to continue. Shifting this question more in the direction of a body refurbished with pharmaceutical treatment, there are similar questions about how ambivalent it can be to attempt to restore one’s body to a previous, “normal”, state.

Statements about being dead were it not for coming to the UK might exemplify the extent of “bare life”, biological life, as the underpinning rationale for legal entry, and for what my informants’ lives were ultimately being defined by at the moment. The ironies of seeing and knowing generosity and compassion only when one is at their most vulnerable in life has not gone unnoticed by others working on the contradictions of care and humanitarianism (Ticktin 2011a). Das (2007) emphasises how the urgency of care in situations of extreme risk, shows a crucial

gesture of humanity. But it is not unproblematic, particularly when we consider the sentiments and feelings that take shape in the aftermath of saving someone:

I am reminded here of the attention Deleuze asks us to pay to what might be *a* life. For him, no one has described *a* life better than Charles Dickens if we take the indefinite article as an ‘index of the transcendental.’ Deleuze goes on to recount the story of a disreputable man held in contempt by everyone. But when he is thought to be dying, those taking care of him show respect and even love, but as soon as it becomes clear that he is not going to die, they go back to their earlier dispositions of contempt toward him. Deleuze asks us to contemplate that moment between his life and death when everyone around him senses that it is a moment characterized only as *a* life playing with death. [Das 2007:91-92, emphasis in original]

A life saved (or savable) demands as much reconciliation as a life ended. There have been suggestions throughout the thesis of the troublesome encounters informants had with charitable bodies, legal authorities, and one another. I have demonstrated the participation and willingness, be it whole-hearted or half-hearted, which make bodily minimums and continuity plausible. If we consider these situations through the prism of the gift (Mauss 1966), a second chance at life, suggests a variety of relations, obligations and refusals: how being able to live with HIV as a chronic illness stretches from the taking of tablets to renewed uncertainty about what other sicknesses the body was capable of; and the way gifts oblige people to their givers and mediate relationships of power. There was no one single gift giver informants could necessarily thank or attribute their living to. Everyone stressed how good their doctors were and how good they were to them, along with other sources of help and kindness they had connected with: counsellors, peer support workers, ministers and solicitors.

At the same time, there was this sense that the continuity of life as they knew it had unfolded as a string of coincidences and accidents. Few had planned on

becoming ill, or on traveling and relocating going wrong. Informants did not refuse the gift of life, and many have embraced it to the best of their ability. But what I hoped to have shown in this chapter is the continuum of inflections about what exactly is good about “being alive”. As Lambek writes, “[...] we cannot simply limit ethics to the goods internal to a set of discrete bounded practices but must examine the juxtaposition of practices and the exercise of judging among incommensurable goods in ‘the art of living’” (Lambek 2010: 23). Indeed, “incommensurable goods” captures well the varying kinds of good informants had to reconcile. Antiretroviral therapy was now a fact of life for my informants and a key object that played a role in putting them in touch with various relationships of “good”: hospitals, doctors and support personnel. And yet there were expectations to be met in order to keep these goods “good” in one’s life. This included adhering to medical guidance, managing symptoms and staying informed. And such discernment was embedded further still in evaluations of other things. Returning to Nancy’s comment mentioned at the start of this chapter, her observation of what she found humane in British society – managing social precariousness also initiated one into sets of relationships and obligations which required diligence and care in their own ways: learning how to ask for help, to accept help, and keeping track of how those charitable relations and acquaintances evolved. The ethnography presented shows how informants seemed burdened not so much with fear of death, but apprehensiveness, and appreciation, for the second chance at life they had been given. This chapter has underscored the limitations of “bare life” for grasping the ordinary thresholds HIV positive migrants such as my informants must come to terms with.

Conclusion

“Any idiot can face a crisis – it’s the day to day living that wears you out”
Anton Chekhov

This thesis has focused on rethinking the trials and experiences implicated in living with HIV and other illnesses in the context of tenuous citizenship in London. I have argued that chronicity is more than routine integration of illness, implicating varying temporalities that elucidate forms of endurance and ordinary ethics alongside finitude. I have stressed how the living and building of a life, and the delaying of their progress, are considerable sources of ambivalence, and attempted to tease apart the different dimensions of biological and social interruptions to the life course. This path of inquiry has taken me down towards the mundane, those realms of living Chekhov so bluntly observed, which can chip away at one’s body and spirit. I have looked at how time goes awry, considering the contradictory dynamics in which the lengthening of biological time for one’s body is juxtaposed with other embodiments and rhythms of time found in senses and inhabiting of place, and personal, social and community relations.

Infectious diseases such as HIV and tuberculosis will continue to be public and community health issues, the prevention and management of which remain critical for minimising the suffering that any serious health condition can cause. In taking up spaces of support groups and communal therapy, and considering what happens inside them, I was interested in the logics of care they were privy to and encouraged to participate in. I have drawn attention to support group settings because these were some of the deliberate ways and forums through which illness was articulated and performed as a potentially routinised thing. These communities and sites were also equally significant for how they attracted people with fragile ties

to the city and who were living in socially, legally and economically vulnerable situations.

As I hoped to have shown, there was at the same time something peculiar about these spaces. Compared to much that was happening in informants' day-to-day lives, these spaces, their offerings and activities were perhaps one of the few non-compulsory things they were a part of – compared to meeting the demands of the state and local authorities with legal documents or presenting one's body for clinical review. This non-obligatory quality gave the groups a sense of being banal despite being made for persons affected by what is still a very troubling disease. The gestures and activities designed, as described throughout the thesis, did not impart any specific urgency, perhaps precisely because they were directed toward the realm of the routine. They were nonetheless a kind of therapeutic intervention, and one worth considering because they demonstrate the enactments necessary to maintain health in illness, and perhaps, conversely, also say something about the current novelties of health, as a demonstration of optimistic feeling, as confidence, as something that is as much achieved, as it is deserved. I have stressed how they are spaces of care that can be reflected on as shot through with their own varieties of humour, social critique and helplessness.

The chapters have foregrounded the multifaceted aspects of migrancy and being betwixt and between the lines of national borders, physical and imagined homes, distant family, strangers and acquaintances, which are unsettling in their own right, and problematise the assurances of a "normal life" with HIV. I have looked at the delays implicated in establishing a clear understanding with the state and its decisions on entry and residence, and have concentrated on how those delays and

periods without clarity, those interruptions, are still lived: in the day-to-day and weekly activities people participate in, in establishing a relationship, or trying to limit intimacy, in the honing of reflections, critiques and complaints. These mundanities are shadowed. I am not arguing that they are inherently rewarding, or that they are gifts people in hardship ought to be grateful for. They are symptoms of a partial and uneasy existence, and they might also be points for thinking through what is modest and spectacular about a second chance at life and living.

This thesis has taken an original approach to bringing together migration and HIV using the framework of chronicity. By considering the reframing of HIV as chronic illness, and the impact of migration on the possibilities and limits of this reframing, I have illustrated the importance of the ordinary. The thesis has been inspired by some of the features of chronic illness management and the language of recovery and optimism it encourages. That is, HIV as an exercise in self-care encourages, implicitly and explicitly, an awareness and appreciation of the everyday and *every day*. Putting these principles into the context of migration, one that I found myself constantly revisiting and rethinking as problems of social immobility and homelessness, the ordinariness of HIV often merged or was subsumed within the folds of the quotidian, perforated with distraction, frustration, boredom and amusement.

I have brought nuance to discussions about how and why migrants with HIV become socialised into sometimes-conflicting roles and identities. Self-help and counselling rhetoric encourage ideas of the self as a free acting agent, capable of choosing positive thoughts over negative ones. At the same time engagement with social and legal institutions, the limitations of their mandates, the conditions and

constraints of their resources, often have disabling and alienating effects. I have underscored the multifaceted nature of migration and settlement, or rather, attempts at settlement, observing the spontaneity and unpredictability of travel and movement, and the risks and consolations that come with putting your trust in people and places you do not know.

Individuals sought to look after their HIV and themselves to the best of their ability, and attending group therapy was a part of that. And yet although my informants were able to defer the death that many were sure would have caught them had they been HIV positive in their home countries, life was still stalled in its own way. Engaging with their chronic illness in a way that almost mimicked the pursuit and promise of normality rather than actually fulfilling that normality, however, was not without its purposes. In circumstances of legal flux or financial duress, taking care of the HIV was sometimes the least upsetting activity they could do, one that did not carry the heartache and trauma of events such as failed romance and friendship, abandoned children, or relying on the goodwill of strangers. The banalities of everyday life brought its own assurances. The HIV could be confined to observing medication and finding ways to eat well on a budget. An everyday not defined by regular work hours and economic productivity was overwhelming in its constraints on what a person could do and where they could go. And yet, it was not impossible to create extraordinary and/or normal moments – be it with a special purchase at a jumble sale, an afternoon volunteering, or a walk through a new street one has never been along.

I am not attempting a sentimental picture of informants' resilience. What I have sought to demonstrate is how the therapeutic surfaces in unpredictable ways

and situations. Without doubt, concerns over citizenship and immigration, and the legitimacy one may or may not be granted by the state, was foremost – and some might argue it provided the very architecture of violence that informants’ were positioned within. I have tried to draw attention to how interruption may be a critical space of time where one does not necessarily wait for a resolution, but establishes an attention to time that acquaints itself with the habitual and the possible. Past trials and disappointments are no less present. When prompted about how life was at the time that they learned about their HIV status, many informants emphasised difficult characters and relationships, and abusive situations. I do not know how much my informants might consider it progress to be able to discuss past wrongs and injuries as we did. I like to think they are in better places now than they were when they first stepped foot in the country. But I also know that chronicity tests one’s finitude and patience, and the potential for “ordinary madness” (Jackson 2008:58) is high. As Biehl and Locke have written, very often anthropologists attempt to get under the skin of unwieldy narratives and subjects that are resistant to technocratic appropriation:

People bear an understanding of their worlds, of the social problems they must circumvent or transcend, and of the kind of politics that would actually serve their aspirations that is unaccounted for in policy discussions and decisions. This is not a subjugated knowledge, constituted unidirectionally by power, but something personal, bearing traces of singularity not easily framed or contained. [Biehl and Locke 2010: 336]

Methodologically, the thesis is distinct as it focused on individual biographies, rather than treating participants as representatives of specific ethnic or cultural groups. I stuck close to informants, often outside of institutional contexts and confines. I aimed to gather a deeper sense of how informants articulated their thoughts and feelings, what they articulated, what subjects or incidents they returned

to. Following suit with other anthropologists who have demonstrated the richness yielded from maintaining a focus on individual lives and biographies (Biehl 2005; Giordano 2008; Niehaus 2012), this thesis has made explicit the continued purchase of individual narrative for elucidating stories of wider social and cultural processes, as well as their effects and implications.

I also hope to have demonstrated how deliberate engagement with an individual life might enable us to gather the frailties and inconsistencies of taken for granted categories and groups of research in medical anthropology. The terms, “African”, “female”, and “HIV positive”, do not necessarily become meaningful on their own or when put together. Epidemiological categories may be sensible to one profession – in how people organise and raise funds to establish projects that make use of them, such as charities run by HIV positive African people – but a close look at individual life trajectories and experiences can quickly reveal the difficulties of coalescing identities in terms of unified culture or ethnic identity. Medical anthropologists have been keen to analyse and critique the complex ways in which health care is delivered, the numerous agencies and professional bodies that often intervene on behalf of groups and populations with ambitious projects and programs. However, in doing so, I think they have also lost sight of the individual bodies and lives that such projects tend to implicate most. Revisiting the form, content and function of individual biography may be a useful corrective, and enable us to think more about what counts as legitimate and useful knowledge in medical anthropology. How and why might ethnographies of institutions and institutional knowledge prove more convincing than knowing the twists and turns of a patient’s life?

The further implications for how medical anthropologists might rethink their understandings of HIV, chronicity, biocitizenship and biosociality, are as follows:

HIV and chronicity

Anthropological studies of HIV interested in the social movements and cultural ideals and sentiments it has spawned, have clarified the resulting disciplinary regimes and obligations persons with HIV are typically subject to, often part and parcel of the exchange for care and resources. The pedagogies of HIV care have been critiqued for furthering neoliberal principles emphasising individual responsibility over social care and political economy. Chronic illness management need not solely revolve around themes of self-surveillance and cultivation as illustrations of how individuals are placed in subject positions with or without their consent. If anything, the material shown here on group therapy suggests more consideration could be paid to the limitations of surveillance as a concept for explaining the nature of people's interest in their condition and body. Further, more attention can be paid to how and why individuals may strive for a certain level of discipline as a means of bringing order to unsettling lives. Some may read my comments as an uncritical cheer for "empowerment". But being interested in the spirit of care people are interested in offering does not mean unbridled acceptance, or that anthropologists should hesitate having debates with informants. Discourses of positive living are socially and politically inadequate and impoverished in numerous ways. However, this thesis has made some concessions to the principles of those support groups I became so familiar with – concessions that have forced me not to be flippant about their projects and intentions.

This thesis has demonstrated the usefulness and potential of chronicity as a concept that can be mined and explored in a number of ways. Most of all, the data here shows the significance of chronicity in terms much broader than that of disease management and integration. It has spotlighted the relevance of the life course, the temporality of its unfolding, and asked how something like HIV is situated within and becomes a part of a temporality that challenges notions of the life course as predisposed to linearity. Informants had many pending situations they were constantly having to balance – time frames that rarely matched up, such as the length of time it took to be recognised as something other than an HIV patient versus the joy of a normal life expectancy with ARTs. Both were long roads occasionally splitting into smaller paths, but returning to drift toward a horizon that remained fuzzy and unclear, making it hard to know what to expect. Questions about when immigration cases would end, when partners would change, when housing could be secured, when they would finally get a solicitor, when they would get to visit home, when they could go back to work, and so forth, meant life often did appear to be a long interruption. I hoped to have shown chronicity necessitates further reflection on the different temporalities simultaneously at play in one's life, their articulations, and the unexpected reworkings of time and migration on and through the body.

Biocitizenship

Biocitizenship continues to be an important concept for understanding how relations with and membership within a particular state are tied to the body and its biology. This thesis has illustrated the continued relevance of debates concerned with the increasingly shrinking pool of resources upon which unsettled and undocumented migrants have to draw on. HIV care and networks afforded my

informants certain links and relationships to care – institutional and informal. It was not necessarily the case though where biology was manipulated or deliberately fashioned as means toward care and visibility. It could be argued that my informants were left with little other than their bodies to establish presence and legitimacy in the country. But whether and how this might have constituted a variety of biocitizenship depends crucially on getting a sense of what is meaningful for participants. As a limited channel through which applications to remain in the country could be made, but as a key element of personal narratives about medication being fundamental to their continued survival, biocitizenship appears here more as a gesture to maintain biological and social legitimacy with existing and potential caregivers or providers of care, even if legal legitimacy from the state was pending. Medical anthropologists could pay more attention to the varieties of biological citizenship operating simultaneously, how their purchase shifts and fluctuates, and their contradictory effects. Attending group therapy for persons living with HIV might demonstrate an interest in being a responsible patient – but there could be a novelty to receiving such a form of community care, or the relatively carefree nature of support groups that is a welcome change to stressful and troubling financial and legal situations. We might also ask how sustainable is the “bio” in biocitizenship in light of chronicity? What exactly does it refer to throughout the life course? Medical anthropologists might explore further the unhinging or severing of “bio” from citizenship, and ask how simply the theme and issues of citizenship are resonant.

Biosociality

Similarly, medical anthropology’s understandings of biosociality could stand being provoked. The data and analysis illustrated here point to a critical rethinking

of what makes biosociality comprehensible and what other kinds of identities or situations might unite people beyond biology? Group therapy for persons with HIV is culturally peculiar in its own way as participants are often assumed to need help reworking all roles, identities and phases in one's life. If diabetics need only learn how to eat again, being HIV positive emphasises how to love and be loved again. But it reaches beyond that as well, as all aspects and areas of living are imagined to intersect with this new task: being a parent, lover, friend, colleague, student, and customer. What does a tenuous biosociality suggest? Under what circumstances is it valued and how does its value and usefulness change? This research suggests medical anthropology reflect on some of the weaknesses and blind spots of its guiding concepts, without completely giving them up.

Further comments on future research

One direction this thesis might spark in terms of future research is more attention to the “aftermaths” of new citizenship and/or postponed citizenship. This could be explored in terms of the impact on 1) varieties of relatedness and solitude; and 2) physical and social movement and mobility.

That I approached people, who were in their middle stages of life, and the middle stages of living with HIV, is not an insignificant feature. Adding on to current and growing research on migrant experiences negotiating with another life after years of waiting, we might also consider refining those questions to bear in mind the stage of life in which those changes are located within. Starting new families in London was something few informants entertained, those with younger

children living in their country of origin were not inclined to have them brought over, citing issues of space and accommodation, expense, and the stress of city life.

Sites of belonging and sociality also warrant further thought. This thesis did not go in-depth into participation in religious and faith communities and that is another aspect that could be approached in novel ways for thinking about how “safe spaces” are constituted: what is social and solitary about such spaces and how much or how little does it have to do with being HIV positive.

Informants’ remarks and responses to my queries about friendship also suggest much more scope for exploration, a line of thought that has not been particularly developed in anthropology and medical anthropology. This could be equally applicable to existing studies of migration and citizenship. Such work could explore further different forms and experiences of intimacy, that go beyond romantic or sexual relations, to ask about relations and dynamics of trust, exchange, and simple pleasures.

And there are more questions about the nature of movement that newly acquired citizenship might generate: going back to home countries and rebuilding kinship ties, or staying in the same place and the changes in micro-geographies in terms of one’s movement through the city – does one begin to experience the city differently, either by a change of routine or change of feelings about security? What stays the same? What persists as a difficulty? Nearly all those I spoke with wanted to work, although many were unsure of their capacities. A number of my informants who were no longer struggling with residency documents were still becoming reacquainted with their own capacities in light of newly acquired rights. What is the impact of having entitlement to work? Does HIV indeed hold as a chronic illness or

do definitions fluctuate to include terms such as disability? What might be some of the unintended or unexpected consequences of citizenship?

What is the future in this context? I noted the awkwardness of asking people about their anticipations for the future. Given that so much of the support group efforts were future-oriented and focused on illustrating potential, how, when and where was the future actually significant? What kind of shape did time have for people, particularly in the longer range of “eventually”? There is a task here for gaining nuance into how the future is qualified.

In taking up the theme of chronicity and exploring it through consideration of two trajectories, one being the evolving of HIV into a chronic illness, and the other in how chronicity might be illustrated in configurations of time, place and living as a person with unsettled residency, this thesis has ventured to take a multifaceted look at what it means for certain kinds of interruption to be prolonged. Furthermore, it has queried how individuals endure and persist, and what insurances and claims take shape about what is, and what would be, right and good in one’s life – whether they are ambitious fantasies or cautious approximations. On the face of it, it would seem my informants had little to live for, other than pharmaceuticals, but as I have illustrated, there were some assurances in the everyday, in the helpful engagements that could be found with different kinds of people: consultants, peer workers, volunteers, and in the passing through of ordinary spaces. But this is not to say there were guarantees. Informants took chances: approaching strangers at airports and on the street, taking the advice of unfamiliar acquaintances, asking friends and family to take care of their children, staying in stressful personal relationships, speaking with students and researchers. Do we need to revise our notions of how and what it

means to seek good in situations of distress? Is it about transcending and finding relief, in faith and spirituality? Should we rethink this polarity of transcendence versus mundaneness?

In her discussion of what migrants without papers in France will do in order to be eligible for legal status on humanitarian grounds, namely, by choosing to remain seriously ill, Ticktin (2006) notes the fundamentally troubled definition of agency that is premised on being disabled, rather than enabled. Furthermore, that the visibility of such persons rests increasingly in the legibility of their biology as evidence of suffering, “[...] how bodies and their biological measures and values allow for and fuel a form of hope for a better life, and yet simultaneously reveal the limited possibilities to enact this hope” (Ticktin 2011b: 141). Ticktin’s reflections capture some of the ironies my informants were met with: how they started off as economic migrants, students and tourists but now were bound to the city as patients with particular social and medical needs. I hope to have shown, though, that there are breaches within situations of duress where senses of mutual bewilderment, appreciation and understanding emerge, and which speak to the continued importance of assessing what makes life liveable.

REFERENCES

- African HIV Policy Network. 2009. From a Destination Unknown to a Safe Place: immigration control and people living with HIV: new policy perspectives. Position paper. London: AHPN.
- Agamben, Giorgio. 1995. *Homo Sacer*. Stanford: Stanford University Press.
- Ahmed, Sara. 2004. "Affective Economies." *Social Text* 22: 117-139.
- _____. 2008. "The Politics of Good Feeling." *Australian Critical Race and Whiteness Studies Association* 4 (1): 1-18.
- Alcano, Matteo Carlo. 2009. "Living and Working in Spite of Antiretroviral Therapies: Strength in chronicity." *Anthropology and Medicine* 16 (2): 119-130.
- Amit, Vered. 2012. "The Raptures and Ruptures of Mobility." *Identities* 19 (4): 501-509.
- Anderson, Bridget. 2010. "Migration, Immigration controls and the Fashioning of Precarious Workers." *Work, Employment and Society* 24 (2): 300-17.
- Anderson, Jane. 2003. "Living with HIV: The Experiences of Migrant Women from Africa in the UK." In *Gender and Insecurity: Migrant Women in Europe*, ed. Jane Freedman, 139-152. Aldershot: Ashgate.
- _____. 2008. "Coming and Going: Some Aspects of Care for Migrants with HIV in the UK." *Journal of Infection* 57 (1): 11-15.
- Baumann, Gerd. 1996. *Contesting Culture: Discourses of Identity in Multi Ethnic London*. Cambridge: Cambridge University Press.
- BBC. 2011. Asylum seekers 'granted amnesty' by UK Border Agency. Available at, <http://www.bbc.co.uk/news/uk-politics-13617183>.
- Becker, Gay. 1998. *Disrupted Lives: How People Create Meaning in a Chaotic World*. Berkeley: University of California Press.
- Benjamin, Walter. 1978. *One-Way Street and Other Writings*. Translators, Edmund Jephcott and Kingsley Shorter. San Diego: Harcourt Brace Jovanovich.
- Berlant, Laurent. 2007a. "Nearly Utopian, Nearly normal: Post-Fordist Affect in La Promesse and Rosetta." *Public Culture* 19 (2): 273-301.
- _____. 2007b. "Slow Death (Sovereignty, Obesity, Lateral Agency)." *Critical Inquiry* 33: 754-780

- _____. 2008. *The Female Complaint: The Unfinished Business of Sentimentality in American Culture*. Durham: Duke University Press.
- _____. 2011. *Cruel Optimism*. Durham: Duke University Press.
- Biehl, Joao. G. 2005. *Vita: Life in a Zone of Social Abandonment*. Berkeley: University of California Press.
- _____. 2007. "Pharmaceuticalization: AIDS treatment and global health politics." *Anthropological Quarterly* 80 (4): 1083-1126.
- Biehl, Joao, and Amy Moran-Thomas. 2009. "Symptom: Subjectivities, Social Ills, Technologies." *Annual Review of Anthropology* 38: 267-88.
- Biehl, Joao, and Peter Locke. 2010. "Deleuze and the Anthropology of Becoming." *Current Anthropology* 51 (3): 317-351.
- British Refugee Council. 2013. Brief Guide to Asylum. Available at, http://www.refugeecouncil.org.uk/assets/0002/5610/Asylum_Briefing_2013.pdf
- Butler, Judith. 1999. *Gender Trouble*. New York: Routledge.
- Carr, E. Summerson. 2009. "Anticipating and Inhabiting Institutional Identities." *American Ethnologist* 36 (2): 317-336.
- Camlin, C. S., Kwen, Z. A., Dworkin, S. L., Cohen, C. R., & Bukusi, E. A. 2014. "'She mixes her business': HIV Transmission and Acquisition Risks Among Female Migrants in western Kenya." *Social Science and Medicine* 102:146-156.
- Carter, Michael. 2008. Deportation from UK of refused HIV-positive asylum seeker to Uganda does not breach human rights, European Court rules. Available at, <http://www.aidsmap.com/en/Email-a-friend/tpl/1412195/page/1430455/Immigration>.
- Chinouya, Martha Judith, and Eileen O'Keefe. 2008. "Pachedu-Zenzele in the Diaspora: Promoting Sexual Health Amongst Zimbabweans in England." *International Migration* 46 (5): 71-93.
- Colvin, Christopher J. 2011. "HIV/AIDS, Chronic Diseases and Globalisation." *Global Health* 7 (1): 31-6.
- Coreil, J., Wilke, J. and Pintado, I. 2004. "Cultural Models of Illness and Recovery in Breast Cancer Support Groups." *Qualitative Health Research* 14 (7): 905-23.
- Day, Sophie. 2010. "Ethics Between Public and Private: Sex Workers' Relationships in London." In *Ordinary ethics: anthropology, language, and action*, ed. Michael Lambek, 292-309. New York: Fordham University Press.

- Del Vecchio Good, M. J., B.J. Good, C. Schaffer, and S. E. Lind. 1990. "American oncology and the discourse on hope." *Culture, Medicine and Psychiatry* 14 (1): 59-79.
- Dench, G., K. Gavron, and M. Young. 2006. *The New East End: Kinship, Race and Conflict*. London: Profile books.
- Desjarlais, Robert. 1994. "Struggling Along: The Possibilities for Experience Among the Homeless Mentally Ill." *American Anthropologist* 96: 886-901.
- _____. 1997. *Shelter Blues: Sanity and Selfhood Among the Homeless*. Philadelphia: University of Pennsylvania Press.
- Doyal, Lesley, and Jane Anderson. 2005. "'My fear is to fall in love again...' How HIV-positive African women survive in London." *Social Science and Medicine* 60 (8): 1729-1738.
- Ehrenreich, Barbara. 2009. *Bright-sided: How the Relentless Promotion of Positive Thinking has Undermined America*. New York: Metropolitan Books.
- European Court of Human Rights. 2008. Case of N v. The United Kingdom. Strasbourg: European Court of Human Rights. Available at, http://www.eschr-net.org/docs/i/case_of_N_v._the_united_kingdom.
- Fassin, Didier. 2009. "Another Politics of Life is Possible." *Theory, Culture and Society* 26 (5): 44 -60.
- Fassin, Didier, and Estelle D'Halluin. 2005. "The Truth from the Body: Medical Certificates as Ultimate Evidence for Asylum Seekers." *American Anthropologist* 107 (4): 597-608.
- Fassin, Didier and Richard Rechtman. 2009. *Empire of Trauma: an Inquiry into the Condition of Victimhood*. Princeton: Princeton University Press.
- Fordham, Graham. 2001. "Moral Panic and the Construction of National Order HIV/AIDS Risk Groups and Moral Boundaries in the Creation of Modern Thailand." *Critique of Anthropology* 21(3): 259-316.
- Fortun, Kim. 2001. *Advocacy After Bhopal: Environmentalism, Disaster New Global Orders*. Chicago: University of Chicago Press.
- Foucault, Michel. 1978. *The History of Sexuality, volume I*. Translated by Robert Hurley. New York: Vintage Books.
- _____. 1980. "The Politics of Health in the Eighteenth Century." In *Power/Knowledge: Selected Interviews and Other Writings 1972-1977*, ed. Colin Gordon, 166-182. New York: Pantheon.

- Freeman, Carla. 2007. "The "reputation" of neoliberalism." *American Ethnologist* 34 (2): 252-326.
- Freud, Sigmund. 1917. "Mourning and Melancholia." In *A General Selection from the Works of Sigmund Freud*, eds. J.R. M.D., 124-140. New York: Doubleday Anchor Books.
- Freud, Sigmund. 1919. "The 'Uncanny'." In *The Standard Edition of the Complete Psychological Works of Sigmund Freud, Volume XVII (1917-1919): An Infantile Neurosis and Other Works*, ed. James Strachey, 217-256. London: The Hogarth Press.
- Garcia, Angela. 2010. *The Pastoral Clinic: Addiction and Dispossession Along the Rio Grande*. Berkeley: University of California Press.
- Gatter, Philip N. 1995. "Anthropology, HIV and Contingent Identities." *Social Science and Medicine* 41 (11): 1523-33.
- Giordano, Cristiana. 2008. "Practices of Translation and the Making of Migrant Subjectivities in Contemporary Italy." *American Ethnologist* 35 (4): 588-606.
- Glick Schiller, Nina, Stephen Crystal and Denver Lewellen. 1994. "Risky Business: The Cultural Construction of AIDS Risk Groups." *Social Science and Medicine* 38 (10): 1337-46.
- Goffman, Erving. 1963. *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs: Prentice-Hall.
- Good, Anthony. 2007. *Anthropology and Expertise in the Asylum Courts*. London: Routledge-Cavendish.
- Gower, Melanie. 2013. Immigration and asylum policy: Government plans and progress made. House of Commons Library Note.
- Green, Linda. 1998. "Lived Lives and Social Suffering: Problems and Concerns in Medical Anthropology." *Medical Anthropology Quarterly* 12 (1): 3-7.
- Guell, Cornelia. 2011. "Candi (e) d action: Biosocialities of Turkish Berliners living with diabetes." *Medical Anthropology Quarterly* 25 (3): 377-394.
- _____. 2012. "Self-Care at the Margins: Meals and Meters in Migrants' Diabetes Tactics." *Medical Anthropology Quarterly* 26 (4): 518-533.
- Hacking, Ian. 1999. *The Social Construction of What?*. Harvard: Harvard University Press.

- Hay, M. Cameron. 2010. "Suffering in a Productive World: Chronic Illness, Visibility, and the space beyond agency." *American Ethnologist* 37 (2): 259-74.
- Holston, James and Arjun Appadurai. 1996. "Cities and citizenship." *Public Culture* 8: 187-204.
- Irving, Andrew. 2005. "Life Made Strange: An Essay on the Reinhabitation of Bodies and Landscapes." In *Qualities of Time: ASA Monograph Vol 41*, eds. Wendy James and David Mills, 317-30. Oxford: Berg.
- _____. 2010. "Dangerous Substances and Visible Evidence: Tears, Blood, Alcohol, Pills." *Visual Studies* 25 (1): 24-35.
- Jacobs, J. M. 1996. *Edge of Empire: Postcolonialism and the City*. New York: Routledge.
- Jain, S. L. 2007. "Living in Prognosis: Toward an Elegiac Politics." *Representations* 98 (1): 77-92.
- Jankowiak, W. R. (Ed.). 2008. *Intimacies: Love and Sex Across Cultures*. New York: Columbia University Press.
- Jaye, C., Egan, T., and S. Parker 2006. "'Do as I say, not as I do': Medical Education and Foucault's Normalising Technologies of Self." *Anthropology and Medicine* 13 (2): 141-55.
- Kelly, Tobias. 2008. "The Attractions of Accountancy: Living an Ordinary Life During the Second Palestinian Intifada." *Ethnography* 9 (3): 351-76.
- _____. 2011. *This Side of Silence: Human Rights, Torture, and the Recognition of Cruelty*. Philadelphia: University of Pennsylvania Press.
- Khan, Nichola. 2013. "A Moving Heart: Querying a Singular Problem of 'Immobility' in Afghan Migration to the UK." *Medical Anthropology* 32 (6): 518-34.
- Klaits, Frederick. 2009. "Faith and the Intersubjectivity of Care in Botswana." *Africa Today* 56 (1): 3-20.
- Kleinman, Arthur. 1997. "'Everything That Really Matters': Social Suffering, Subjectivity, and the Remaking of Human Experience in a Disordering World." *The Harvard Theological Review* 90: 315-335
- _____. 2014. "How we endure." *The Lancet* 383 (9912): 119-120.

- Lakoff, Andrew. 2010. "Two Regimes of Global Health." *Humanity: An International Journal of Human Rights, Humanitarianism, and Development* 1 (1): 59-79.
- Lambek, Michael (ed.). 2010. *Ordinary Ethics: Anthropology, Language, and Action*. New York: Fordham University Press.
- Le Marcis, Frederic, and J. Inggs. 2004. "The Suffering Body of the City." *Public Culture* 16 (3): 453-77.
- Lyttleton, Chris. 2004. "Fleeing the Fire: Transformation and Gendered Belonging in Thai HIV/AIDS Support Groups." *Medical Anthropology* 23 (1): 1-40.
- Levy, Jennifer M., and Katerini T. Storeng. 2007. "Living Positively: Narrative Strategies of Women Living with HIV in Cape Town, South Africa." *Anthropology and Medicine* 14 (1): 55-68.
- Malkki, Liisa. 1995. *Purity and Exile: Violence, Memory, and National Cosmology Among Hutu Refugees in Tanzania*. Chicago: University of Chicago Press.
- _____. 1996. "Speechless Emissaries: Refugees, Humanitarianism, and Dehistoricisation." *Cultural Anthropology* 11 (3): 377-404.
- Marsland, Rebecca. 2012. "(Bio) Sociality and HIV in Tanzania: Finding a Living to Support a Life." *Medical anthropology quarterly* 26 (4): 470-85.
- Marsland, Rebecca, and Ruth Prince. 2012. "What Is Life Worth? Exploring Biomedical Interventions, Survival, and the Politics of Life." *Medical anthropology quarterly* 26 (4): 453-69.
- Martin, Emily. 1994. *Flexible Bodies: The Role of Immunity in American Culture from the days of Polio to the Age of AIDS*. Boston: Beacon Press.
- _____. 2007. *Bipolar Expeditions: Mania and Depression in American Culture*. Princeton: Princeton University Press.
- Marshall, Thomas H. 1964. *Class, Citizenship and Social Development*. New York: Doubleday and Company, Inc.
- Mauss, Marcel. 1966. *The Gift: Forms and Functions of Exchange in Archaic Societies*, trans. Cunnison. London: Cohen & West.
- Michael Jackson. 2008. "The Shock of the New: On Migrant Imaginaries and Critical Transitions." *Ethnos: Journal of Anthropology* 73 (1): 57-72.
- Mol, Annemarie. 2008. *The Logic of Care: Health and the Problem of Patient Choice*. New York: Routledge.

- Muehlebach, Andrea. 2011. "On Affective Labor in Post-Fordist Italy." *Cultural Anthropology* 26 (1): 59-82.
- Napolitano, Valentina. 2007. "Of Migrant Revelations and Anthropological Awakenings." *Social anthropology* 15 (1): 71-87.
- National AIDS Trust. 2008. HIV & the Asylum Pathway. Available at: <http://www.nat.org.uk/Our-thinking/People-in-greatest-need/Asylum%20and%20migration.aspx>.
- Negri, Antonio, and Michael Hardt. 1999. "Value and Affect." *Boundary 2*, 26 (2): 77-88.
- Niehaus, Isac. 2012. *Witchcraft and a Life in the New South Africa* (Vol. 43). Cambridge: Cambridge University Press.
- Nguyen, Vinh-kim. 2005. "Antiretroviral Globalism, Biopolitics, and Therapeutic Citizenship." In *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems*. eds. A. Ong and S. J. Collier, 124-44. Malden: Blackwell.
- Orton, Lois Catherine. 2009. Seeking Asylum and Living with HIV, An Ethnographic Study. PhD dissertation. Manchester: University of Manchester.
- Orton, Lois, J. Griffiths, M. Green, and H. Waterman. 2012. "Resilience Among Asylum seekers living with HIV." *BMC Public Health* 12 (1): 926.
- Pandolfo, Stefania. 2007. "'The burning': Finitude and the Politico-theological Imagination of Illegal Migration." *Anthropological theory* 7 (3): 329-63.
- Petryna, Adriana. 2002. *Life Exposed: Biological Citizens after Chernobyl*. Princeton: Princeton University Press.
- _____. 2004. "Biological citizenship: The Science and Politics of Chernobyl Exposed Populations." *Osiris* 19: 250-26.
- Rabinow, Paul. 2008. "Artificiality and Enlightenment: From Sociobiology to Biosociality." In *Anthropologies of Modernity: Foucault, Governmentality, and Life Politics*. Ed. J. X. Inda, 179-93. Hoboken: John Wiley & Sons.
- Rasmussen, Louise Mubanda, and Lisa Ann Richey. 2012. "The Lazarus Effect of AIDS Treatment: Lessons Learned and Lives Saved." *Journal of Progressive Human Services* 23 (3): 187-207.
- Rhine, K. A. 2009. "Support Groups, Marriage, and the Management of Ambiguity among HIV-positive women in northern Nigeria." *Anthropological Quarterly* 82 (2): 369-400.

- Ridge, D., I. Williams, J. Anderson, and J. Elford. 2008. "Like a Prayer: the Role of Spirituality and Religion for People living with HIV in the UK." *Sociology of Health and Illness* 30 (3): 413-428.
- Robbins, Joel. 2013. "Beyond the Suffering Subject: Toward an Anthropology of the Good." *Journal of the Royal Anthropological Institute* 19 (3): 447-696
- Robins, Steven. 2004. "Long live Zackie, long live': AIDS activism, Science and Citizenship after Apartheid." *Journal of Southern African Studies* 30 (3): 651-72.
- . 2006. "From "rights" to "ritual": AIDS activism in South Africa." *American Anthropologist* 108 (2): 312-23.
- Rock, Melanie. 2003. "Sweet Blood and Social Suffering: Rethinking Cause Effect Relationships in Diabetes, Distress, and Duress." *Medical Anthropology* 22 (2): 131-174
- Rose, Nikolas, and Carlos Novas. 2005. "Biological Citizenship." In *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems*. eds. A.Ong and S. J.Collier, 439-463. Malden: Blackwell.
- Rotter, Rebecca. V. E. 2010. 'Hanging in-between': Experiences of Waiting among Asylum Seekers Living in Glasgow. PhD dissertation. Edinburgh: University of Edinburgh.
- Sales, Rosemary. 2002. "The Deserving and the Undeserving? Refugees, Asylum Seekers and Welfare in Britain." *Critical Social Policy* 22 (3): 456-78.
- . 2005. "Secure Borders, Safe Haven: A Contradiction in Terms?" *Ethnic and Racial Studies* 28 (3): 445-62.
- Sangaramoorthy, Thurka. 2008. "Invisible Americans: Migration, Transnationalism, and the Politics of Difference in HIV/AIDS Research." *Studies in Ethnicity and Nationalism* 8 (2): 248-66.
- Sered, S. ,and E. Tabor, E. 1999. ""You Are a Number, Not a Human Being": Israeli Breast Cancer Patients' Experiences with the Medical Establishment." *Medical anthropology quarterly* 13 (2): 223-52.
- Seremetakis, C. Nadia (Ed.). 1996. *The senses still*. Chicago: University of Chicago Press.
- Sharp, Lesley. A. 2006. *Strange Harvest: Organ Transplants, Denatured Bodies, and the Transformed Self*. Berkeley: University of California Press.
- Simmel, Georg. 1903. "The metropolis and mental life." In *The Urban Sociology Reader*, eds. Jan Lin and Christopher Mel, 23-31. New York: Routledge.

- Songwathanaa, Praneed and Lenore Manderson. 2001. "Stigma and Rejection: Living with AIDS in villages in southern Thailand." *Medical Anthropology* 20 (1): 1-23.
- Sontag, Susan. 1989. *Illness as Metaphor and AIDS and It's Metaphors*. New York: Picador.
- Ticktin, Miriam. 2006. "Where Ethics and Politics Meet: The Violence of Humanitarianism in France." *American Ethnologist* 33 (1): 33-49.
- _____. 2011a. *Casualties of Care Immigration and the Politics of Humanitarianism in France*. Berkeley: University of California Press.
- _____. 2011b. "How Biology Travels: A Humanitarian Trip." *Body and Society*, 17(2/3): 139-158.
- UNHCR. 1951. The 1951 Convention relating to the Status of Refugees. Geneva: UNHCR. Available at, <http://www.unhcr.org/3b66c2aa10.html>.
- Ussher, J., Kirsten, L., Butow, P., and Sandoval, M. 2006. "What do Cancer Support Groups Provide which other Supportive Relationships do not? The Experience of Peer Support Groups for People with Cancer." *Social Science and Medicine* 62 (10): 2565-76.
- Van Dongena and Ria Reis. 2001. "Editorial: Chronic illness: Struggle and Challenge." *Medical Anthropology* 19 (4): 293-97.
- Vigh, Henrik. 2008. "Crisis and Chronicity: Anthropological Perspectives on Continuous Conflict and Decline." *Ethnos: Journal of Anthropology* 73 (1): 5-24.
- Wainana, Binyavanga. 2005. "How to write about Africa." *Granta magazine*. Available at, <http://www.granta.com/Archive/92/How-to-Write-about-Africa/Page-1>
- Waldby, Catherine, and Robert Mitchell. 2006. *Tissue Economies: Blood, Organs, and Cell Lines in late Capitalism*. Durham: Duke University Press.
- Werner, Anne, and Kirsti Malterud. 2003. "It is Hard Work Behaving as a Credible Patient: Encounters between Women with Chronic Pain and their Doctors." *Social Science and Medicine* 57 (8): 1409-19.
- Whittaker, Andrea M. 1992. "Living with HIV: Resistance by Positive People." *Medical Anthropology Quarterly* 6 (4): 385-90.
- Whyte, Susan Reynolds. 2009. "Health Identities and Subjectivities: The Ethnographic Challenge." *Medical Anthropology Quarterly* 23 (1): 6-15.

_____. 2012. "Chronicity and Control: Framing 'Noncommunicable Diseases' in Africa." *Anthropology & Medicine* 19 (1): 63-74.

_____. 2013. Keynote address. Society for Medical Anthropology, June 2013, Tarragona, Spain.

Willen, Sarah S., Jessica Mulligan, and Heide Castañeda. 2011. "Take a Stand Commentary: How can Medical Anthropologists Contribute to Contemporary Conversations on "Illegal" Im/migration and Health?" *Medical Anthropology Quarterly* 25 (3): 331-56.

Wirth, Louis. 1938. "Urbanism as a Way of Life." *American journal of Sociology* 1 24.